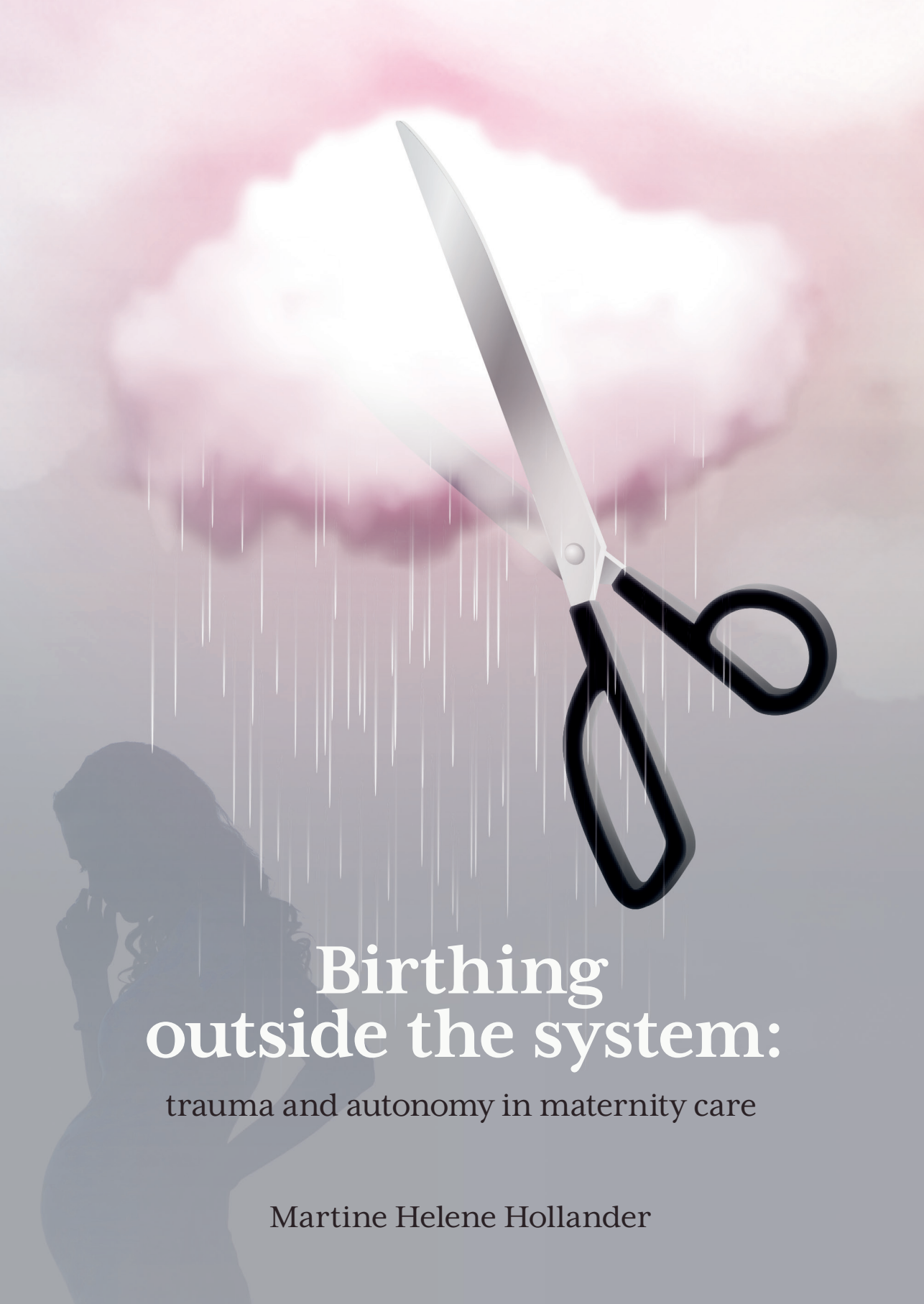

Birthing outside the system:

trauma and autonomy in maternity care

Martine Helene Hollander

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General introduction

General introduction

Jeske is expecting her first child. She has had a difficult childhood, and not many friends or family. The pregnancy is complicated by severe pelvic pain and she has difficulty walking. Around the due date, labor starts suddenly and one contraction quickly follows another. She calls her midwifery practice, and a locum midwife, whom she has never seen before, comes to her house. After several hours and only two centimeters of dilation, she asks her midwife for pain relief and she is transported to the hospital for an epidural. Jeske feels that the anesthetist is in a hurry. "I was forced to sit cross-legged and couldn't move. Meanwhile it was one contraction after another." Pain relief is suboptimal, and Jeske is surrounded by unknown people. She remembers being told to lay on her back without much explanation, and an electrode is placed on the baby's head. When she reaches complete dilation, she is told to start pushing, even though she feels no urge. She is left pushing with a nurse for 45 minutes, after which an obstetrician enters. All she remembers of this is him saying: 'I am here to help you.' The next things she remembers is that he "pushes the ventouse in", without much in the way of explanation. She has no idea what to do, but tries to push. It is in vain. She is taken to the operating room for an emergency cesarean section.

At the follow-up appointment six weeks later, Jeske has recovered well physically, but nobody asks her how she feels about the birth. She has recurring nightmares, and has been experiencing vaginism ever since, which was never an issue for her before.

('Jeske', which is not her actual name, has read her story as presented here and has given permission for it to be used.)

Jeske's story is an example of how maternity care, conducted according to guidelines and protocols and carried out by maternity care providers with the very best intentions, can result in trauma for the women involved. This trauma may cause some women to decide to avoid future medical care, or decline certain parts of recommended care for their next pregnancy and birth. These phenomena gained national attention in the Netherlands in 2013, when three community midwives were tried by the medical disciplinary committee for delivering assistance during home births in high risk pregnancies[1]. Home births in high risk pregnancies were not unheard of in the Netherlands, even prior to this court case. Also in 2013, the Amsterdam UMC, AMC had started a designated clinic for women who planned to go against medical advice in their choices surrounding birth, including those planning a home birth in a high risk

1 https://zoek.officielebekendmakingen.nl/stcrt-2014-18656.html

pregnancy[2,3,4,5]. However, the court case referenced here was the first time midwives were prosecuted for attending home births in high risk pregnancies, since this was considered an undesirable development by both the Health Care Inspection, who initiated the court case, and many maternity care providers in the country. All three midwives were reprimanded, and one was struck off, although the latter verdict was overturned on appeal and converted to a one-year's license suspension. The reasoning by the court of appeals in this case was that second best care, for instance a midwife attending a high risk home birth, was preferable to no care at all, providing the woman in question had been adequately counseled. The reprimands and suspension were, among other reasons, due to the fact that insufficient case notes were made by the midwives to prove that they had recommended hospital care and that the women in this case had been adequately counseled about the risks they were taking. The ruling of the court of appeals was cause for concern for many community midwives in the Netherlands, because it was made clear that conflicting interests could occur in situations where women 'demand' care outside protocols and midwives don't feel comfortable providing such 'second best care', for which they may feel unequipped, unqualified and which can make them feel emotionally vulnerable. This ruling stressed the urgency of further research into the phenomenon of women disregarding medical advice and giving birth at home in a high risk pregnancy, or choosing unassisted childbirth (UC), and led to the inception of this thesis.

2 https://www.amc.nl/web/ik-heb-een-afspraak-1/mijn-afspraak-in-het-amc/poli-ondersteuning-maatwerk-zwangerschap-geboorte-pom-polikliniek.htm

3 https://www.trouw.nl/home/goed-gesprek-helpt-bij-weigermoeder-die-per-se-thuis-wil-bevallen~ab1f0831/

4 http://www.maia-verloskundigen.nl/geldersevallei/_sitefiles/file/De%20Graaf%202014%20-%20NTOG%20-%20recht%20op%20verloskundige%20zorg%20(2).pdf

5 https://www.nataal.nl/artikelen/artikelen/zwangerschap-bevalling/rek-in-de-richtlijn-de-poli-op-maat-3827/

Magnitude of the problem: what is known?

It is currently unknown exactly how many women choose to have an unassisted childbirth in the Netherlands each year, although this number has been estimated to be around 200[6], which makes up approximately 0.12% of all births. There are no data at all on the number of Dutch women choosing home birth in a high risk pregnancy. Why women would make these choices has also never before been investigated in the Netherlands. However, several studies from other countries have been published on the motivations of women to choose high risk birth options, which are summarized in a recent scoping review of 15 studies by Holten and De Miranda.[7] The themes found in this review were: resisting the biomedical model of birth by trusting intuition, challenging the dominant discourse on risk by considering the hospital as a dangerous place, feeling that true autonomous choice is only possible at home, perceiving birth as an intimate or religious experience, and taking responsibility as a reflection of true control over decision-making. The studies used for this review all originated in countries where home birth is not institutionalized: Finland, Sweden, the United States, Australia, or is a marginal phenomenon: Canada. Unfortunately, no studies had yet been done in countries with an integrated home birth system, such as New Zealand, the United Kingdom, or the Netherlands, with its maternity care system known for a physiological approach to childbirth and the general acceptance among both public and professionals of home birth as a regular option for healthy women with a low risk pregnancy. Because of this physiological approach, it may seem all the more surprising that the phenomenon of 'birthing outside the system' also occurs in the Netherlands.

However, the apparent increase in women who choose to go against medical advice in their birth choices could be seen in the context of other developments of the last decade. In 2008, the Netherlands saw the publication of the first PERISTAT (Perinatal Statistics) report, in which perinatal health indicators of 29 European countries were compared[8]. The perinatal mortality rates of the Netherlands were relatively high in comparison to other high income countries. This prompted the Ministry of Health to appoint a Steering Group Pregnancy and Childbirth (Stuurgroep Zwangerschap en Geboorte), which produced a report making suggestions for increasing safety around pregnancy and

6 Verbeek A. Baren buiten het boekje. Tijdschrift voor Verloskundigen 2013;2013:40–4.

7 Holten L, de Miranda E. Women's motivations for having unassisted childbirth or high risk homebirth: an exploration of the literature on 'birthing outside the system'. Midwifery 2016;38:55–62 (July).

8 http://www.europeristat.com/reports/national-perinatal-health-reports.html

childbirth in the Netherlands[9]. These suggestions centered around putting mother and child first, sharing information between echelons, organization of maternity care and 24/7 availability of obstetricians in hospitals, but also led to an increased emphasis on protocols in an attempt to increase quality of care. Furthermore, this period saw the introduction of perinatal audit in the Netherlands in 2010, an increasing number of hospital mergers and an increase in the average size of midwifery practices.[10] Viewing women's motivations for making birth choices against medical advice known from the international studies mentioned above in light of these changes in Dutch maternity care and this increase in (adherence to) protocols may explain the emergence of the phenomenon of birthing outside the system in the Netherlands.

In addition, it has been known for some time that not all women remember the day they gave birth fondly. A recent meta-analysis showed that, in community samples, 2.9% of women developed post partum PTSD (Post Traumatic Stress Disorder)[11]. A Dutch study by Rijnders et al. found that 16.3% of low risk women look back negatively on giving birth[12]. What was not yet known is why some women found giving birth traumatic, and which women are particularly vulnerable to traumatic birth experiences.

9 https://www.nvog.nl/wp-content/uploads/2018/02/Advies-Stuurgroep-zwangerschap-en-geboorte-1.0-01-01-2009.pdf

10 M.H. Hollander en J. van Dillen. Zorg op maat in de verloskunde, verklaard vanuit de geschiedenis. NTOG 2017;vol. 130

11 Grekin R, O'Hara M.W. Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis. Clin Psychol Rev. 2014; 34(5): 389-401

12 Rijnders M, Baston H, Schönbeck Y, van der Pal K, Prins M, Green J et al. Perinatal factors related to negative or positive recall of birth experience in women 3 years postpartum in the Netherlands. Birth 2008; 35(2):107–116

Outline of this thesis

The purpose of this thesis was to find answers to the following questions:

1) What is the legal position of women who do not want to follow medical advice during pregnancy and childbirth, in the Netherlands and elsewhere? What are ethical considerations? Are there limits to autonomy and how do the rights of the unborn child effect all of this?

To place the current situation in the Netherlands in an international perspective, we performed an analysis of international legal and ethical literature on women refusing care during pregnancy. We also studied national and international protocols, guidelines, practice bulletins and laws. The results of our search can be found in Chapter 2.

2) What are the motives underlying the choice of some medium or high risk Dutch pregnant women to deliver at home? What are the motives underlying the choice of some women for an unassisted birth? What is the emotional impact of 'outside the system' requests on Dutch midwives and obstetricians, and how does this affect the way they practice?

To answer these questions, the WONDER-study (Why women want Other or No DElivery caRe) was conceived[13]. Ninety-one interviews were carried out with women, partners, obstetricians, community midwives and holistic midwives. Community midwives usually work in group practices, where client base and on calls are shared. 'Holistic' midwives are relatively new in the landscape of Dutch maternity care. There is no set international definition of what a holistic midwife is, but for the purposes of this thesis they have been defined as midwives who frequently work as case-load midwives. They are often willing to honor requests for care that do not align with protocols or guidelines. The results of these interviews can be found in Chapters 3, 4 and 5.

Most of the women were contacted through an open call on the facebook website of the 'birth movement' (Geboortebeweging), or referred through midwives that we knew through our own practice, or from this facebook group. An attempt was made to gather together as many different points of view per case as we could, therefore we asked as many women as feasible if we could also interview their partner, their holistic midwife and their community midwife and/or obstetrician, if applicable. The results of those pooled data can be found in Chapter 7.

13 https://www.amc.nl/web/leren/research-62/research/wonder-studie.htm

3) How often do Dutch obstetric and midwifery care givers receive requests for care against medical advice and guideline/protocol? What is the attitude of these professionals delivering obstetrical care towards women who wish to give birth 'outside the system'?

For another part of the WONDER-study, we devised and disseminated a survey among all registered gynecologists, trainees, regular midwives and holistic midwives, some of whom were unregistered. We asked about how often they encountered requests for the above mentioned care, how they felt about this in terms of their professional autonomy and comfort zone, and what their approach towards these special requests from women was. The results can be found in Chapter 6.

4) What causes women to experience childbirth as traumatic? Is there anything we, as maternity care providers, could have done differently during the birth to prevent this? Is there something the women themselves would have done differently in hindsight? What are risk factors for a traumatic birth experience? Is there anything we can do during pregnancy to prepare women better for giving birth? Can we identify which women are particularly vulnerable and as a result prevent traumatic birth experiences?

In order to answer these questions, we devised the TEACH-study (Traumatic Experiences Associated with CHildbirth)[14]. We designed a questionnaire which was disseminated through social media. The only inclusion criterion was for women to have experienced at least one birth as traumatic, based on their own estimation. The survey contained several validated questionnaires to estimate the objective presence of 'trauma' and PTSD (Post Traumatic Stress Disorder). We asked not only the particulars of the birth, but also what we, and they themselves, might have done differently to prevent the traumatic experience. The results of this survey can be found in Chapter 8 (TEACH 1) and Chapter 9 (TEACH 2).

5) Finally, we wanted to evaluate what kind of requests against medical advice we had encountered at our designated clinic. What were the maternal and perinatal outcomes in terms of perinatal mortality and NICU (Neonatal Intensive Care Unit) admissions, and severe maternal morbidity, and in how many cases had we been able to reach a compromise with our patients? How many cases had ended up inside protocol, and how many had chosen to disregard our advice and deliver elsewhere?

14 http://traumatischebevalling.nl/

All women who attended our designated clinic were registered prospectively during a period of three years. The results of our negotiations, including place of birth and final outcome, were analyzed and can be found in Chapter 10.

Part 1

The WONDER-study

Instead of asking: "Why don't women want the service we offer?"
we should ask: "Why don't we offer the service women want?"
(WHO 2005)

2

Women refusing standard obstetric care: maternal-fetal conflict or doctor-patient conflict? Legal and ethical considerations

J Preg Child Health 2016, 3:2
Martine Hollander, Jeroen van Dillen, Toine Lagro-Janssen, Evert van Leeuwen, Wilma Duijst and Frank Vandenbussche

Abstract

Objectives:
Some women choose to give birth outside medical protocol or ignore medical advice. This could be perceived as a maternal-fetal conflict. Many professionals are unsure about the legal possibilities and ethical intricacies in these circumstances, and the position of the fetus. This paper attempts to elucidate and provide a framework for these issues.

Methods:
We did a literature search on Pubmed in October 2014, using the terms "legal/law", "pregnant/pregnancy", "legal measures", "court-ordered caesarean/cesarean", "birth", "childbirth" and "home birth". We also reviewed some professional organizations' guidelines.

Results:
Much has been written about legal restrictions and measures against women who go against medical advice, for instance court-ordered cesarean sections or forced hospital admissions. Medical professionals fear litigation in case of a bad outcome when the mother's wishes are respected. However, medical assessment of risk and benefit is sometimes inaccurate. Maternal competence is a central issue.

The pregnant patient has the right to autonomy, bodily integrity, freedom and self-determination and the fetus has the right to have its life protected. However, it is unethical to invade one person's physical integrity for the benefit of another, especially if the other is not born yet. Religious rights are generally respected, but this is not unlimited.

International guidelines on this subject generally state that a competent pregnant patient has the same rights as any other person and that her autonomy should prevail.

Conclusions:
In contrast to the general perception the conflict described is not between mother and child but between doctor and patient. Communication can be the key to solving this problem. In cases of continued disagreement, the mother's autonomy should prevail.

Introduction

Evidence based guidelines can help healthcare practitioners to provide better and more cost effective care for the average patient with a specific medical problem (1). During the past 15 years, the Cochrane Collaboration, NICE, and many other national and international organizations have provided obstetric medicine with a wealth of new evidence based guidelines. However, more protocollized care also means less room for personalized medicine. Not all patients have the same perception of risk as medical staff (2), and some attach more importance to avoiding a certain intervention (for instance cesarean section) than to incurring a small increase in risk of perinatal morbidity or mortality. One of the consequences of the plethora of protocols in obstetric medicine could be a real or perceived increase in the number of patients who wish to go outside the standard of care. No quantitative surveys on this subject have been done to date, so exact numbers are not available. Much is still unclear among professionals about the rights of a pregnant woman, those of her fetus, and the legal position of a healthcare provider who is willing to assist a woman who wants to give birth outside the standard protocol. The debate is as yet unresolved whether the law can or indeed should intervene in situations where the woman's decision seems to put the fetus's life at risk. This is often described by obstetricians as a maternal-fetal conflict. In this paper we will provide some insight into the legal and ethical context surrounding women's rights in childbirth and the issues mentioned above. We will also review some professional organizations' statements on these issues.

Legal measures against pregnant women in literature

For the purposes of this paper, we were interested in the legal position of women who desire to give birth outside the current medical protocols. This constitutes giving birth at home against medical advice, or giving birth unattended by any medical professional (freebirth or unattended childbirth). We did a literature search on Pubmed in October 2014, using the terms "legal/law", "pregnant/pregnancy", "legal measures", "court-ordered caesarean/cesarean", "birth", "childbirth" and "homebirth". We found many publications detailing how women's choices in pregnancy and childbirth have been restricted and punished by both criminal and civil law. A full review of this issue was written by Cherry (3) and provided many of the examples used below. Much of this literature originates in the United States and concerns civil law. In the 1980's and 90's a substantial number of papers were written about court-ordered cesareans (COC). The first reported case occurred in 1981, and concerned a patient with complete placenta previa (4). She refused cesarean section on religious grounds

and a court order was obtained to enforce the procedure, citing a state interest in the welfare of the term fetus. However, before the section could be performed she went into labor and delivered vaginally without major problems. Another well known case is the one of Laura Pemberton, a Florida woman who attempted a home birth after a previous cesarean section. Her doctors judged that she needed a repeat cesarean and obtained a court order from a judge to have her forcibly removed from her home. She underwent a cesarean section under protest and subsequently had three more vaginal deliveries (5). Cherry reports a case of a woman being arrested for fear of her giving birth unattended by a health care professional (3). In 1987, Kolder et al (6) published the first review of known COC cases. They also included one case of forced blood transfusion to a pregnant Jehovah's witness. Notably, a large proportion of the patients who had legal action taken against them for non compliance with doctors' recommendations were poor, black, unmarried and on welfare.

It is notoriously difficult for medical professionals to accurately predict fetal outcome. Annas, in 1982, described two cases of COC in the United States. The first case involved another woman with placenta previa who was judged by her doctors as having 99 percent chance of fetal death in case of a vaginal delivery. A COC was ordered, but in the mean time she delivered vaginally and had a healthy child. In the second case the attending obstetrician diagnosed fetal distress. The COC was performed nine hours later and the child was born in good condition (7). Recently, a Florida court compelled a pregnant woman to undergo a cesarean section against her wishes after premature rupture of membranes at 25 weeks. She had wanted to go home and get a second opinion but her physician sought and obtained a court order. The COC was performed three days later and resulted in a stillbirth (8). In contrast, Elkins reported two cases in 1989, one of which was an unwanted pregnancy where a COC was sought for fetal distress. It was denied and an intra partum fetal death occurred. In the other case, the pregnant woman was diagnosed with severe depression. A COC was performed for fetal distress and the baby was born alive but acidotic. Both of these women were in the hospital for the first time and had not had any chance of discussing their wishes prior to the described emergency (9).

Many other interventions and measures against pregnant women have been reported in criminal law literature. In the United States, some states can give the court jurisdiction over unborn children when the mother habitually uses drugs or alcohol (5, 10). This means that pregnant women can be taken into custody and sentenced to prison for child endangerment when they use illicit substances. This has led to 12 states requiring physicians to report drug use in pregnancy to child welfare agencies (3). We have been unable to find any reference to action being taken against a pregnant woman for smoking cigarettes or being

overweight, even though these are also well established risk factors for a number of unfavorable outcomes. However, documented cases include women being arrested for exposing their unborn child to dangerous fumes, for not following doctors' orders to take bed rest, and for taking a long time to get to the hospital while in labor or while bleeding (5, 11). Cherry (3) describes a case where a judge sentenced a pregnant woman to prison for credit card fraud to prevent her from having the opportunity to obtain the abortion she announced she wanted. By 1999, more than 200 US women were on record for having been arrested for endangering fetal health.

Legal measures have also been taken after the fact: several mothers have been charged with murder after refusing a cesarean section deemed necessary to save the life of their child (12-14). Bowes, in 1981, cited jurisprudence where "the fetus may be the victim of homicide if born alive but dies as a result of prenatal injury" (15). And even if the child survives, it can later sue it's mother in civic court for actions taken by her that may have adversely affected the child's development prior to birth (11). This paves the way for any number of legal issues surrounding choices pregnant women, or indeed parents, make regarding their (unborn) children. Although less has been published on this subject in recent years, court-ordered cesarean sections are by no means a thing of the past. Margolin described a case in 2014 in Israel where medical staff was given carte blanche by the court to perform any examination or intervention deemed necessary in order to prevent damages to the fetus and the patient herself (16). In a survey performed among the heads of maternal-fetal medicine fellowships in the United States in 1987, many thought that pregnant women who endangered their fetus's life should be detained and that forced treatment under those circumstances was acceptable (6). Adams in 2003 and Samuels in 2007 did similar surveys and found that, although the willingness to go against patient's wishes by taking legal action had significantly decreased, still every interviewee could envision conditions under which they would ultimately take such a step (13, 17).

In the matter of legal involvement with women's decisions in pregnancy, competence is a central issue. When unconscious, a patient is incompetent. In that case, consent can be assumed for interventions deemed necessary to prevent death or serious harm to the patient. Competence can also be in question in cases of severe mental illness or a state of drug-induced decreased mental capacity (18, 19), although this does not necessarily imply that a patient with any psychiatric problem is automatically legally incompetent. In addition, the vast majority of pregnant women, regardless of whether or not they agree with the treatment their physician suggests, are legally competent. However, some physicians find it difficult to imagine how a person of sound mind could possibly

disagree with the proposed plan of treatment. Cahill wrote about this in 1999: "There seems to be a blanket assumption of maternal incompetence: women who refuse recommended treatment cannot be of sound mind"(20). But, as Cherry (3) states: "the making of poor choices does not generally constitute mental disease or defect".

In this era of malpractice lawsuits, physicians are, understandably, afraid when patients make choices that, in the opinion of the doctor, may increase the chance of harm to the fetus. However, we have found no reported cases in the literature where a health care professional was found guilty of negligence by a court for respecting a competent patient's wishes (21). Therefore these fears appear to be unfounded. On the other hand, overruling the patient may leave the treating physician open to allegations of assault and battery (22). Legal concerns have led doctors to be guided by fear and to practice defensive medicine (23). Many daily obstetrical decisions are made based on risks, without knowing exactly how high those risks are. Medicine itself seems to be moving more and more towards a risk based, preventative approach, where pathology is defined by a standard deviation of the norm. A recent survey done among young (mostly female) obstetricians in Canada showed that they, compared to their older, predominantly male predecessors, were more likely to favor technology during birth in order to maintain control, and were less appreciative of the role of women in their own birth (24).

Ethical considerations: do the rights of the mother conflict with those of the child?

Informed consent and shared decision making are important principles of current medical practice. Health care professionals outline the different treatment options with the accompanying risks and benefits, and the patient decides. Although the patient may make another decision than the doctor would make, this has not led to doctors forcing patients to undergo surgery or a medical therapy that the patient does not wish, even if it leads to the untimely demise of the patient. Obstetrics is different and unique in the sense that many health care professionals feel that there are two patients involved: mother and fetus, and doctors feel they are equally responsible for both. If the mother makes a decision that the professional feels may put her child at risk, it may be emotionally difficult to accept this. In the greater part of the twentieth century, the aim of prenatal care in the developed world was reducing maternal mortality. In recent decades, with the arrival of ultrasound and fetal monitoring, the fetus has become much more visible during pregnancy and has now become the main focus of prenatal care. Pregnant patients are offered genetic counseling, fetal aneuploidy screening and ultrasounds for structural defects. It seems natural

that, with increasing visibility of the fetus, more importance is being attached to its rights and wellbeing. In weighing the wishes of the mother against fetal interests, numbers needed to treat and numbers needed to harm play a role, as well as the valuation of the different outcomes. It is a well known fact that medical professionals frequently disagree amongst each other in the estimation of risks and benefits, and also in their advice (6). If a decision that a pregnant woman makes with regard to her pregnancy increases the chances of fetal harm by a certain margin, that is not the same as saying that the fetus will certainly come to harm.

Autonomy, bodily integrity, freedom and self determination are important principles in modern society. Pregnant women should be no exception. However, freedom and self determination are not absolute. They can be curtailed if necessary to prevent harm to others, for instance in the case of mandatory isolation during an outbreak of an infectious disease (25). With growing medical knowledge of the fetal condition in utero there are more arguments being made for fetal rights (26). The question then becomes: is the fetus an "other" in the eyes of the law (22)? This leads directly to the debate on personhood. What constitutes a person? The law in many countries states that one has to be born to be a person. However, the case for personhood for the fetus is, counter-intuitively, largely grounded in abortion law. If abortion is illegal after viability is attained, does this not automatically mean that the fetus at that point gains certain rights to have its life protected? And if a woman does not choose abortion, has she de facto accepted that the fetus is a person and even subordinated her personal rights to the fetus's right to life? This is described by Draper (27) as a slippery slope: we do defend the rights of the fetus in the respect that we can't end its life any time the mother wants, but as long as it is not born, the mother's wish prevails.

Next we should look at forced interventions on pregnant women for the benefit of their fetus. In order to protect one from harm, we would have to do harm to the other. The question is: is it ethical to inflict harm on one person against their will to prevent harm to another? Some have attempted to answer this question by comparing the maternal-fetal "conflict" to that of one person being forced to donate an organ for the benefit of another (the US legal case of McFall vs Shimp). This reasoning has never been approved by a court, not even in the case of a deceased person who during life had chosen not to become an organ donor after death. Do we then award pregnant women fewer rights than deceased people or fetuses more rights than people who have already been born? Of course, this comparison is unfair to the extent that, in most cases, the harm to the mother would be temporary and would not leave any lasting physical scars, with the exception of a forced cesarean section. However, if we

would, under certain circumstances, be willing to take away the mother's autonomy for the benefit of her fetus, where would that lead us? Forced bed rest for threatening preterm labor? Mandatory cessation of smoking in pregnancy, punishable by fines or incarceration? Some women have claimed religion as a reason for refusing to follow medical advice (4). Although freedom of religion is an important right in modern society, religious rights have also been the focus of much social debate. For instance, male circumcision is widely accepted in many western countries as either a cultural or religious requirement, whereas female genital mutilation, for those same reasons, has generally been outlawed, even in countries where it is widely practiced. Therefore, there are limits to freedom of religion, where it concerns decisions parents make for their children. Whether or not a child is actually born can be a deciding factor. For instance, a Jehovah's witness can refuse a blood transfusion for herself, even when she is pregnant. However, once her child is born and needs a blood transfusion to survive, a court may relieve the parents of their parental rights in order to be able to override their refusal. If, for example, a 36 weeks pregnant rhesus negative woman with decreased fetal movements comes to the hospital and ultrasound reveals severe fetal anemia, she may refuse an intrauterine transfusion, based on religious reasons. But how would we value her decision if, after consultation with her religious leaders, she also refuses induction of labor in order for a pediatrician to perform a neonatal transfusion?

Guidelines by professional organizations regarding the issue of maternal-fetal conflict

Many professional organizations have created guidelines on how to handle situations of perceived maternal-fetal conflict. The American Congress of Obstetricians and Gynecologists states: "Pregnant women's autonomous decisions should be respected. Concerns about the impact of maternal decisions on fetal well-being should be discussed in the context of medical evidence and understood within the context of each woman's broad social network, cultural beliefs, and values. In the absence of extraordinary circumstances, circumstances that, in fact, the Committee on Ethics cannot currently imagine, judicial authority should not be used to implement treatment regimens aimed at protecting the fetus, for such actions violate the pregnant woman's autonomy" (28). The Australian Medical Association says: "A pregnant woman has the same rights to privacy, to bodily integrity, and to make her own informed, autonomous health care decisions as any competent individual, consistent with the legal framework of that jurisdiction. A pregnant woman's capacity to make an informed decision should not be confused with whether or not the doctor (medical practitioner) considers her decision to be reasonable, sensible or

advisable. A doctor may not treat a competent pregnant woman who has refused consent to treatment. Recourse to the law to impose medical advice or treatment on a competent pregnant woman is inappropriate" (29). In addition, the American Academy of Pediatrics counsels that "court intervention should be sought only in rare cases and should be seen as a last resort to be undertaken with great caution" (30). The Royal College of Obstetricians and Gynaecologists in the United Kingdom finds that: "It is inappropriate and unlikely to be helpful or necessary to invoke judicial intervention to overrule an informed and competent woman's refusal of a proposed medical treatment, even though her refusal might place her life and that of her fetus at risk" (31). Recently, the World Health Organization released a statement on "The prevention and elimination of disrespect and abuse during facility-based childbirth" (32).

Conclusion

Medical professionals working in obstetrics often feel as if there are not one but two patients to consider: the pregnant woman and her unborn child. In recent years, the way in which medicine is practiced has changed, due to increased evidence and protocols. Where the medical professional trusts in the protocol, some patients may feel more comfortable putting their faith in their own body's ability to give birth without (a certain amount of) medical intervention. As shown in the examples mentioned in this paper, professionals frequently disagree on the preferred course of action and are sometimes incorrect in their estimation of fetal danger. In some cases this may lead to a situation where doctor and patient disagree on the treatment plan. If the patient opts for a course that could lead to a perceived increase in risk for the fetus, the doctor may feel that there is a conflict between mother and fetus, where in reality it is the doctor and the patient who are at odds. The best solution to this problem is not to be found in legal action taken against the mother, but in communication between doctor and patient. Counseling patients with respect for their individual circumstances, background, opinions and convictions, and being open and honest about risks, benefits, and uncertainty, will in most cases be sufficient to resolve the problem. In some select cases, an agreement can not be reached. In those cases, it may be advisable to discuss the patient's wishes in a multidisciplinary setting. Panelists could be obstetricians, midwives, nurses, legal and ethical experts and social workers, and even the patient herself. The aim of such a discussion is to attempt to reach a compromise with which both patient and medical staff feel comfortable. If a compromise can not be reached, the autonomy of the patient, according to professional guidelines, should prevail.

References

1) Talaulikar V, Nagarsekar U. Evidence-Based Medicine: An Obstetrician and Gynaecologist's Perspective. J Obstet Gynaecol India 2012 Apr;62(2):146-53. doi: 10.1007/s13224-012-0173-5. Epub 2012 Jul 31.
2) Jackson M, Dahlen H, Schmied V. Birthing outside the system: Perceptions of risk amongst Australian women who have freebirths and high risk homebirths. Midwifery 28 (2012) 561-567.
3) Cherry A. The Detention, Confinement, and Incarceration of Pregnant Women for the Benefit of Fetal Health. Research Paper 07-139, March 2007, Cleveland-Marshall College of Law.
4) Finamore E. Jefferson v. Griffin Spalding County Hospital Authority: Court-Ordered Surgery to Protect the Life of an Unborn Child. Am J L&Med. 83 1983-1984.
5) Paltrow L. Roe v Wade and the New Jane Crow: Reproductive Rights in the Age of Mass Incarceration. Am J Public Health 2013;103:17-21.
6) Kolder V, Gallagher J, Parsons M. Court-ordered obstetrical interventions. N Eng J Med. 1987 May 7;316(19):1192-6.
7) Annas J. Law and the Life Sciences: Forced Cesareans: The Most Unkindest Cut of All. The Hastings Center Report, Vol. 12, No. 3 (Jun., 1982). Pp. 16-17+45.
8) Charles S. Obstetrics and Violence Against Women. Am J Bioethics, 11:12, 51-56: Dec 2011.
9) Elkins T, Andersen F, Barclay M, Mason T, Bowdler N et al. Court-ordered cesarean section: An analysis of ethical concerns in compelling cases. Am J Obstet Gynecol;July 1989:150-154.
10) Ikemoto L. Forced cesareans. Current Opinion in Obstetrics and Gynaecology. Volume 10(6), December 1998, pp 465-468.
11) Johnsen D. A New Threat to Pregnant Women's Autonomy. The Hastings Center Report, Vol. 17, No. 4 (Aug. – Sep., 1987), pp. 33-40.
12) Symon A, Winter C, Dip P, Donnan P and Kirkham M. Examining Autonomy's Boundaries: A Follow-up Review of Perinatal Mortality Casus in UK Independent Midwifery. Birth 37:4 December 2010.
13) Samuels T-A, Minkoff H, Feldman J, Awonuga A and Wilson T. Obstetricians, health attorneys, and court-ordered cesarean sections. Women's Health Issues 17 (2007) 107-114.
14) Marwick C. Mother accused of murder after refusing caesarean section. BMJ Volume 328 20 March 2004.
15) Bowes W and Selgestad B. Fetal Versus Maternal Rights: Medical and Legal Perspectives. Obstetrics and Gynecology Vol. 58, No. 2, august 1981.
16) Margolin J, Mester R. Medical treatment without a patient's consent and against her will. Harefuah 2014 Mar-Apr, 153(3-4): 139-41, 241.
17) Adams S, Mahowald M, Gallagher J. Refusal of treatment during pregnancy. Clin Perinatol 30 (2003) 127-140.
18) Hondius A, Stikker T, Wennink J, Honig A. The law for special admission for psychiatric illness applied to an addict in early pregnancy. Ned Tijdschr Geneeskd. 2011;155:A3818.
19) Schneider A, Raats M, Blondeau M, Steegers E. Pregnant, addicted prostitutes: some forced admissions in the interest of the child. Ned Tijdschr Geneeskd. 2004 2 october;148(40).
20) Cahill H. An Orwellian Scenario: court ordered caesarean section and women's autonomy. Nurs Ethics 1999 6: 494.
21) Nelson L. Legal Dimensions of Maternal-Fetal Conflict. Clinical Obstetrics and Gynecology, Vol 35, nr 4, December 1992.
22) Rossiter G. Contemporary transatlantic developments concerning compelled medical treatment of pregnant women. Aust NZ J Obstet Gynaecol. 1995 May;35(2): 132-8.
23) Bishop T, Federman A, Keyhani S. Physician's View on Defensive Medicine: A National Survey. Arch Intern Med 2010;170(12):1081-1083. doi:10.1001/archinternmed.2010.155.
24) Klein M et al. Attitudes of the New Generation of Canadian Obstetricians: How Do They Differ from Their Predecessors? Birth 38:2 June 2011.

25) CDC, http://www.cdc.gov/quarantine/aboutlawsregulationsquarantineisolation.html (accessed May 2nd 2015).
26) Thampapillai D. Court-ordered obstetrical intervention and the rights of a pregnant woman. (2005) 12 JLM 455-461.
27) Draper H. Women, forced caesareans and antenatal responsibilities. Journal of Medical Ethics 1996;22:327-333.
28) ACOG Committee Opinion number 321, November 2005 en 664, June 2016.
29) AMA Position Statement on Maternal Decision making, 2013.
30) American Academy of Pediatrics (AAP) Committee on Bioethics: Fetal therapy: ethical considerations. Pediatrics. 1988 Jun;81(6):898-9.
31) Royal College of Obstetricians and Gynaecologists (RCOG) Ethics Committee guidance 1993.
32) WHO, http://apps.who.int/iris/bitstream/10665/134588/1/WHO_RHR_14.23_eng.pdf?ua=1&ua=1 (accessed May 2nd 2015).

3

Women's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis

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Abstract

Background

Home births in high risk pregnancies and unassisted childbirth seem to be increasing in the Netherlands. Until now there were no qualitative data on women's motivations for these choices in the Dutch maternity care system where integrated midwifery care and home birth are regular options in low risk pregnancies. We aimed to examine women's motivations for birthing outside the system in order to provide medical professionals with insight and recommendations regarding their interactions with women who have birth wishes that go against medical advice.

Methods

An exploratory qualitative research design with a constructivist approach and a grounded theory method were used. In-depth interviews were performed with twenty-eight women on their motivations for going against medical advice in choosing a high risk childbirth setting. Open, axial and selective coding of the interview data was done in order to generate themes. A focus group was held for a member check of the findings.

Results

Four main themes were found: 1) Discrepancy in the definition of superior knowledge, 2) Need for autonomy and trust in the birth process, 3) Conflict during negotiation of the birth plan, and 4) Search for different care. One overarching theme emerged that covered all other themes: Fear. This theme refers both to the participants' fear (of interventions and negative consequences of their choices) and to the providers' fear (of a bad outcome). Where for some women it was a positive choice, for the majority of women in this study the choice for a home birth in a high risk pregnancy or an unassisted childbirth was a negative one. Negative choices were due to previous or current negative experiences with maternity care and/or conflict surrounding the birth plan.

Conclusions

The main goal of working with women whose birthing choices do not align with medical advice should not be to coerce them into the framework of protocols and guidelines but to prevent negative choices.

Recommendations for maternity caregivers can be summarized as: 1) Rethink risk discourse, 2) Respect a woman's trust in the birth process and her autonomous choice, 3) Have a flexible approach to negotiating the birth plan using the model of shared decision making, 4) Be aware of alternative delivery care providers and other sources of information used by women, and 5) Provide maternity care without spreading or using fear.

Background

The Netherlands are often praised by natural childbirth advocates and heralded as a haven for physiological, natural (home-) birth. However, in spite of the fact that home birth is still a valid and respected option within the system in the Netherlands, it has been declining in recent decades. Healthy women without a problematic medical or obstetrical history or pregnancy complications can still opt for home birth with a midwife, but more and more women are referred to the hospital either in pregnancy or during birth for an increasing number of indications, including women's own requests [1]. On the other hand, many Dutch obstetricians and midwives have the impression that a growing number of women refuse to be referred. They choose home birth against medical advice, with or even without a midwife present. This has become a 'trending topic' of many conferences and symposia in the Netherlands in the last three years. However there is, as yet, no statistical data to support this impression. These choices can give rise to legal and ethical dilemmas, as described in several publications [2-4].

In a recent scoping review, Holten and de Miranda found fifteen studies on the motivations of women choosing unassisted childbirth (UC), home birth in countries where home birth was not well integrated into the maternity care system, or a midwife-attended high-risk home birth [5]. The countries involved were Australia, Canada, Finland, Sweden, the United Kingdom (UK) and the United States of America (USA) . Women in these studies who chose to give birth 'outside the system' often put their trust in their own intuition, thereby resisting the biomedical model of birth and challenging the dominant risk discourse by considering the hospital as a dangerous place. These women often perceived birth as an intimate or spiritual experience. They felt that true autonomous choice was only possible at home. For some women in these studies, taking full responsibility for the birth outcome (good or bad) was a reflection of true control over decision-making. The key conclusion of this review was that 'concerns over consent, intervention and loss of the birthing experience might be driving women away from formal healthcare and that there is a lack of fit between the health needs of some pregnant women and the current system of maternity care in several high-income countries' (p.55). Furthermore, the authors argue that a dialogue on views on superior knowledge, risk, autonomy and responsibility should take place between women and their health care providers.

Also recently, two similar studies from the UK reported that women often feel that their rights are violated: UC is legal, but not always treated as such by professionals [6,7]. Therefore they have to plan tactically and keep their intentions a secret. They believe they are judged by social services to be unfit as

a mother. The authors also found that participants objected to professionals only talking in risks, and felt subjected to a system dominated by fear of a bad outcome.

It is tempting to attribute the choice that women make for home birth in a high risk pregnancy or UC in the countries mentioned above to a lack of physiological approach to childbirth and high percentage of interventions. However, in the Dutch system the same phenomenon is seen, even though midwifery care and home birth for low risk women are integrated in the maternity care system and rates of interventions (for instance induction of labor, use of analgesia and caesarean section) are still relatively low. This is despite an increase of referrals from primary to secondary care in the last decade [8]. Therefore it is necessary to look beyond increasing medicalization and access to home birth, and examine Dutch women's motivations and their negotiation with medical professionals in maternity care to elucidate this issue.

To this end the WONDER-study (Why women want Other or No DElivery caRe) was conceived. We used a mixed methods study to explore the motivations of Dutch women who have chosen to give birth 'outside the system' (e.g. against medical advice and/or guideline/protocol or UC) and the experiences of midwives and obstetricians regarding care for these women. In this paper we present the results of in-depth semi-structured interviews with twenty-eight women on their motivations for choosing home birth in a high risk pregnancy or UC and their approach to realise the intended birth of their choice.

Methods

For the purpose of fully reporting the process of data collection and analysis of the findings, the COREQ criteria were used [9]. For this study, permission was sought from the medical ethics committees of the Radboud University Medical Center Nijmegen and the Academic Medical Center in Amsterdam. Both deemed the study as not requiring permission.

Research team

All interviews were conducted by one of three authors (MH, LH and EdM), who are also women and researchers with a professional interest in women's motivations to give birth outside the guidelines. All have a medical background in midwifery/obstetrics and had experience with in depth interviews. One (LH) had extensive previous experience with qualitative research as a medical anthropologist. Prior to the interviews, none of the subjects were known to the interviewers, either personally or professionally. However, there had been email

contact with all participants, asking for their participation and explaining the reasons, goals and methods of the study and the identity and background of the interviewer.

Study design

This study consists of exploratory qualitative research using a constructivist approach and a grounded theory method [10]. Participants were selected through several sampling methods: purposive (approaching certain nationally known advocates or famous "cases"), convenience (contacting potential participants who happened to be posting on an online maternity care users forum during the time of recruitment) and snowball (referral of some participants by other participants or their midwives, who were informed about the study by the researchers). The sole criterium for inclusion was one or more births "outside the system". Before the start of the study consideration was given to the question whether women who had a UC and women who had a midwife who attended their high risk home birth should be analyzed in the same study. Halfway during the interviews it became clear that the motivations and perspective of women in both groups were very similar. Therefore the decision was made to include all of the participants in this study. All participants were approached by online methods. There were no refusals or drop-outs. All participants gave informed consent for their quotes to be used in this article. All but one of the interviews took place at the home of the participants. One interview was held in the Academic Medical Center in Amsterdam by the participants' request, for logistic reasons. Demographic data of the participants are shown in Table 1. The interviews were semi-structured by the use of a topic list [Figure 1], which was based on themes known from the literature [5] and questions the researchers had themselves, though the interviews were allowed to flow naturally. Certain topics (e.g. defining moment, search for alternative care) were added later during the study as they had been mentioned by participants in earlier interviews. All interviews were recorded by digital sound recorder and transcribed verbatim either by a commercial company or by volunteer medical students. The interviews lasted between 30 and 120 minutes, and some field notes about atmosphere and personal observations were made afterwards. All sound files, transcripts and informed consent forms were stored anonymously in a secured password protected university digital storage system.

Data analysis

Data were analyzed by two of the authors (LH and MH) using qualitative data analysis software (MaxQDA). Before the start of coding and twice during the coding process (after approximately ten and twenty interviews) LH and MH

Table 1 Maternal characteristics (N=28, involving 35 deliveries)

Maternal characteristics	N
Indication for secondary care	21
VBAC (1 also diabetes type I)	8
Breech (1 also post term)	5
Twins (1 also preterm)	3
Previous postpartum hemorrhage (>1000 ml) or manual placenta removal	2
Prelabor rupture of membranes > 24 hours	1
High body mass index (> 35)	1
Treatment with low molecular weight heparin	1
Unassisted childbirth (UC)	**7**
Age at delivery (years)	
20-25	2
>25-30	18
>30-35	8
>35-40	7
Parity during relevant delivery	
1	8
2	13
3	8
4	4
5	1
6	1
Employed	
Yes	19
No	9
Highest education	
High School	4
Vocational training	4
College	6
University	14
Marital status at time of relevant delivery	
Married	20
Living together	8
Perinatal death	2
Breech	1
VBAC	1

coded the same interview and discussed the differences in coding in order to check intercoder reliability and reach consensus. The coding was started bottom up and expanded and built on during each additional interview. After approximately ten interviews an interim thematic analysis was done, and themes from this were then incorporated into the topic list for subsequent interviews. Data saturation was reached after analysis of the first 22 interviews; analysis of a further six interviews confirmed this. The final coding tree [Figure 2] was decided on by consensus between LH and MH after all coding had been completed. Transcripts were not returned to the participants. Instead, to validate and discuss the themes that were found, a feedback focus group was held. Six participants were purposefully selected from the fourteen who were willing to participate in this because of their different stories and obstetric histories. Two of the authors (MH and LH) translated the quotes that are used from Dutch to English.

Figure 1 Topic List. List of topics used during the interviews

Medical situation (high risk) in this and previous pregnancies
What did you want to do that was against medical advice?
Why?
What makes a good birth or a bad birth?
Relationship with maternity care provider (time, connection, needs)
Trust (in care provider, in yourself, in protocols, in evidence, in the system)
Preparation (people, sources)
Partner's position
Risk perception (yours, care provider's, how to weigh these)
Autonomy (informed consent, equality, control)
Fear (for what? Why?)
Needs (physical, emotional, social)
Deciding moment (to deviate from protocol)
Search for alternative care(-r)

Results

Twenty-eight women were interviewed. After grounded theory analysis of all interviews four major themes emerged: "Discrepancy in the definition of superior knowledge", "Need for autonomy and trust in the birth process", "Conflict during negotiation of the birth plan" and "Search for different care". After careful consideration of the data it became clear that one overarching core category connected the four major themes and all their sub-themes, and this was fear.

Discrepancy in the definition of superior knowledge

All participants described a discrepancy between the views of their regular maternity care providers and their own views regarding risk perception of childbirth. In their experience, the professionals' starting point was a biomedical framework based on protocols and guidelines, in which (screening for) risk factors and using interventions to minimize risk was the mainstay of their approach. The participants had differing views on childbirth which can roughly be divided into two schools of thought. One group used a traditional biomedical framework, but weighed risks and benefits differently from their providers. For instance, they believed that the negative consequences of the suggested procedures far outweighed the possible prevention of harm. Because of this, they were prepared to accept the small increase in risk that refusing certain interventions entailed. This group questioned the applicability of the evidence used by medical professionals because they believed that the optimal way to approach childbirth (for instance a breech on all fours) had never been tested against the current standard. Also, these participants believed guidelines and statistics applied to large groups but have very limited use for the individual woman.

> *"I found the risk of a uterine rupture of 0.4% acceptable. Because other than that I had absolutely nothing. […] [Weighed] against the risk of intervention or even another caesarean in the hospital. […] so I came to a 0.4 for me, individually" (R18, home VBAC (vaginal birth after cesarean), second child)*

The other group used a nature-oriented framework, wherein a pregnant woman's intuition is considered superior knowledge. They deemed childbirth only safe if left alone and taking place undisturbed in an atmosphere of relaxation (usually at home), where the woman can follow her intuition. However, giving birth in the stressful environment of a hospital, or even at home in the presence of a midwife, would lead to more interventions, making the situation less safe.

> *"I believe that I could get some of the same answers with my intuition, that you could measure in the hospital with machines. […] Your own consciousness could also give you signals, a sense of what needs to happen next" (R1, home breech birth, first child)*

Several participants also believed that the way a child was born and the atmosphere it was born into would have an effect on its development in later life.

"I think many UC women believe, I know I do, that many problems growing up and being human (…) are rooted in how we are born. (…) When I look at society and how harsh and cold it has become and how individual, I think: yes, I am not surprised when you see how we are all born. I see a connection there. " (R6, UC, second and third child)

Need for autonomy and trust in the birth process

Many participants expressed a strong need for autonomy during labor and delivery. They stated that, in their experience, midwives and obstetricians often did not ask for consent before performing invasive procedures (for example episiotomies, rupturing membranes, performing an assisted vaginal delivery or even a cesarean section). Many were traumatized by this during a previous delivery, which contributed to their decision to reject medical advice this time.

[…] "And he rammed that vacuum pump in, literally. Like that! He said: 'I am not here for my own amusement, I am here to help you.' And he rammed […] that vacuum pump in without consultation [with me]. […] And then it was a C section. […] And I think it is mostly because I had that C section. […] and if there would not have been that last traumatic part that doctor X [gynaecologist] came in...[...] then I don't think that I would have necessarily ended up here [giving birth at home]." (R18, home VBAC, second child)

Participants also mentioned the need to feel safe, loved and respected during their delivery, and be surrounded by people who trusted in their ability to give birth unaided, which they felt would not be possible in the regular system.

"[My midwife] wanted to know what was going on and she wanted to perform examinations, and I knew for sure that she would not be 'hands off'. That was stressful for me and I became nervous every time I thought about it. […] I didn't want someone who wanted to examine me and did not trust me and therefore I couldn't trust my body and I would produce stress hormones." (R2, home breech birth, first child)

For some, the process of an undisturbed natural birth was (almost) equally as important as the outcome, as it was part of the personal development of the mother in becoming who she wanted to be: an autonomous woman without fear. Most participants believed that a birth without interventions would be more likely to lead to the desired outcome of an (emotionally and physically) healthy mother and baby.

> *"It can be so affirming, a delivery. It is such a lifelong effect, your experience. […] And yes, I have really become a different person through that delivery because I really faced all my fears. Because I really did it myself and it wasn't the midwife who 'did' my birth." (R3, UC, third child)*

Some participants who had chosen a UC indicated that, in their experience, health care providers believed they were responsible for the outcome of a delivery, whereas the participants themselves insisted that true autonomy was only possible when they were allowed to take full responsibility for their own decisions and whatever outcome that would lead to.

> *"I am the woman who is giving birth, so I am ultimately responsible, even if you are standing next to me, I am still responsible for what I decide to do.[…]" (R5, UC, fourth, fifth and sixth children)*

When discussing her midwives' reaction to her intention to give birth unassisted, the same participant later said:

> *[…]"Their fear reaction was: 'Yes, but then we are responsible for something we are not present for.' Which I felt did not make sense, because you are not there, so you can't be responsible either. But they were very afraid of repercussions if things went wrong, or that we would hold them accountable […]." (R5, UC, fourth, fifth and sixth children)*

Noticeably, none of the participants regretted their choice to birth outside the system, not even the two whose baby did not survive.

> *"For me it feels very clear […]. That now my conscience does not bother me and that I can imagine that would be more the case if I had not been able to make my own decisions surrounding the birth." (R28, home breech perinatal death, first child)*

Conflict during negotiation of the birth plan

Most of the participants started in regular care during the index pregnancy, by which we mean the first pregnancy in which they chose to deliver "outside the system. For many, the decision to give birth at home (or unattended) against medical advice was made sometime over the course of the pregnancy. Many times, one of the deciding factors was a conflict over (part of) the birth plan. Items that were often grounds for discussion were birth positions or the desire for a water birth in a high risk pregnancy. As one participant, who experienced a uterine rupture during a home VBAC, said:

"And [the gynecologist] said to me, 'I can't offer you that bath', but if she had, I think that would have convinced me to choose the hospital. And it may be stupid to say, was it really just that water birth, that made you take all those risks […]? Yes, I did that. […] We did not take that decision lightly. […] An instinctive knowing that that is the way I could give birth AND that it was denied me last time and I let that happen." (R23, attempted home VBAC, second child)

Another participant, who experienced a perinatal death during a home breech delivery, stated:

"In the hospital it was very likely that I would have to give birth lying on a bed, I was afraid of that too. [...] and I felt a very strong fear: if I had to lie down I would not be able to get him out. I had to be able to move around. [...] In our experience we were not impossible to talk to about this subject...[...] no." (R28, home breech, perinatal death, first child)

Also, some participants desired to waive certain parts of the protocol, for example continuous CTG (cardio-tocography) monitoring during VBAC. Most participants felt they encountered insufficient flexibility on the part of their provider. According to them, discussions about the birth plan often involved manipulation on the part of their providers, including threats of perinatal mortality if protocol was not followed. This has become known amongst many participants as 'playing the dead baby card', also known as 'shroud waving' in English literature [7].

"In between I had an unpleasant consultation, [the obstetrician said] 'Yes, at 41 weeks it will be a C-section (cesarean section).' I thought: why? And: 'You don't want a dead child and that we will end up across from each other in court?' So within five minutes we had a grim discussion." (R15, home VBAC, second child)

This negotiation then led to feelings of anger, disappointment and stress on the part of the participants. In quite a few cases, the decision to go against medical advice had negative consequences for the women involved. Some had child protective services forced on them, and many felt they had to operate in secret because of this and the stigma it involved.

Only two of the 28 women did not encounter conflict in the negotiation of their birth plan. One involved a positive first choice for UC with full (stand-by) support of a midwife. The second woman started care with an alternative midwife, possibly without realizing that this midwife did not adhere to national protocols.

Search for different care

Many times, there was a "defining moment" (often a conflict or major disagreement) during antenatal discussions with an obstetrician or midwife, which led to the participants' decision to give birth elsewhere, alone, or with another (often "holistic") midwife. Frequently, this midwife would be a single practitioner, often specializing in working outside the guidelines, and providing continuity of care both during pregnancy and delivery. Many participants indicated that they experienced a lack of continuity of care (-r) in regular care. Some were under the care of a group midwifery practice, with anywhere from four to a dozen midwives. Others were cared for in a hospital, and saw many different obstetricians, residents and clinical midwives during the course of their pregnancy. Some had started a previous birth in primary (midwifery-led) care, but were transferred during birth to a clinical setting due to a complication, at which point their own midwife left them in the hands of hospital staff they had never met before.

Often, women turned to social media, for instance certain facebook groups like "the birth movement", to find confirmation and inspiration for their choices, and to connect with a "holistic" midwife. In some cases, communicating with like-minded individuals and providers through the internet confirmed women in their decision to make a different choice, whereas in other cases their minds had already been made up.

> *"[After finding out the baby was breech] And then I cried in the car. [...] And then I thought: yes, now it won't be a home birth any more. […] Then I cried for I think another hour. Then I went on the internet and joined the birth movement […]. And then within an hour I had somebody who said: 'I will help you at home together with your [own] midwife.'"(R17, home breech birth, first child)*

> *" I was about 34 weeks I think and then I joined the Free Birth Group on Facebook and there was [midwife] too. [A friend] said: [midwife] is first-rate. I could say whatever I wanted and she would do it. So I called [midwife]." (R20, home VBAC, second child)*

Some participants quickly found a likeminded new caregiver, others searched for quite some time and experienced rejection (of their wishes) by yet another midwife or obstetrician.

> *"[…] I had really called or approached every [midwifery] practice in [the city] and they all had the same story, so I felt like either you all have that same protocol that you follow to the letter, OR you have discussed me [between yourselves], but I*

noticed I could not get a foot in the door." (R11, high BMI (body mass index), home birth second child)

Some participants proceeded with their pregnancy without medical help. They checked their own blood pressure, measured their own abdominal circumference, or had an ultrasound done to check for placental location. Some of those who planned a UC devised emergency plans for the most common critical situations, like shoulder dystocia or post partum haemorrhage, whereas others notably did not, since they trusted that an uninterfered-with birth would not go awry.

"[…] I had instructed my partner that if I...suppose I were to lose a lot of blood, really a great deal of blood....the bath fills quickly but you can certainly see the difference.... if you couldn't see my legs any more [...]. But mostly that he had to pay attention to me. If I seemed somewhat distracted or sleepy, that he had to call [the alarm number]."(R5, UC, fourth, fifth and sixth children)

Many of the participants spent a significant amount of time preparing for birth. They read books, took antenatal classes (often hypnobirthing) and talked with family and friends about their decision. Although every participant discussed her situation with her partner at length, it is noticeable that most stated that their partner left the search for information and the final decision completely up to her.

Fear

Women felt that their care provider's version of superior knowledge, with its evidence based protocols, stemmed from fear. Most participants believed that an optimal birth could only be achieved through true autonomy and trust in the natural process, and that this was only possible without fear. According to the many of the participants, conflicts often arose because of fear: where health care providers were afraid of a bad outcome or litigation (or both), women feared unnecessary interventions, being overruled and losing their autonomy, having their birth disturbed (by interventions), being reported to social services and being stigmatized for their choices. These conflicts were an important factor in women's search for a care provider and/or birth setting without fear.

"That CTG or that doptone is also based on fear. Yes, then you trust the machine more than what I tell you about how it's going, or your own intuition. And I understand that you think, as a midwife, you don't want to be sued, and you don't want a dead child, and you feel responsible. I understand all that. But it takes away my control over my delivery and my body and what I want." (R6, UC, second and third child)

The participants in the feedback focus group acknowledged the four main themes as generally fitting with what they had told the interviewers, although several had difficulty with the term fear. They were concerned that fear as an overarching theme would make them appear to be weak and afraid, whereas they viewed themselves as strong, enlightened and determined. The authors therefore emphasize how the theme fear does not just reflect on the participant's fear of unnecessary interventions, but much more on the medical approach of childbirth at this time, with its fear of bad outcome, peer pressure and legal measures.

Figure 2 Code Tree

Discrepancy in the definition of superior knowledge

- Biomedical perspective
  - Biomedical knowledge
    . Risk (Individualisation, Guidelines)
  - Ethics
  - Interventions
    . Aversion hospital (Treatment by hospital staff)
  - System
- Nature oriented framework
  - Acceptance
  - Effect on child
    . Agency foetus
  - Environment important
  - Intuition
    . Awareness
    . Body Knowledge
  - Natural process
  - Religion/spirituality/fate
    . Supernatural

Need for autonomy and trust in the birth process

- Autonomy
  - Control
  - Informed consent
    . Time
    . Information
  - Personal choice
  - Responsibility

Figure 2 Continued

- Emotional needs
  - Feelings of safety
  - Intimacy
    . Love
  - Relaxation
  - Respect
- Personal development
  - Process equally important as outcome
  - Motherhood
  - Perfection
    . Guilt
- Trust
  - Undisturbed Birth
    . Own pace
    . Hands off

Conflict during negotiation of the birth plan

- Birth plan
  - Flexibility
  - Birth positions
  - Water birth
- Negotiation
  - Negative Feelings/emotions
    . Anger
    . Disappointment
    . Doubt
    . Failure
    . Fear
    . Sadness
    . Stress (Tension)
    . Traumatic experience
  - Consequences
    . Accountability
    . Advocacy
    . Litigation
    . Regret
    . Safety
    . Secrecy
    . Stigma
  - Communication
    . Discussion (Conflict, Manipulation, "Dead baby card")
  - Mismatch

Figure 2 Continued

Search for different care

- Alternative care
  - Persuasion by alternative carer
- Defining moment
- Influence of others
  - Family and friends
  - Partner
  - Social media and the internet
- Preparation
  - Antenatal classes
  - Emergency plan
- Referral
  - Second best choice
  - Willingness to be referred
- Satisfaction
  - Continuity of care(-r)

Discussion

This qualitative study involved 28 in-depth interviews with women who made choices for their birth setting that went against medical advice. Four main themes and one overarching theme emerged. These will now be rephrased as positive recommendations and discussed with reference to the literature.

Rethinking risk discourse

The central concept of the first theme, "Discrepancy in the definition of superior knowledge", is risk discourse. Emphasis on risk has in recent decades become a dominant aspect of clinical discourse, where obstetricians and midwives use protocols and guidelines to minimize risk of morbidity and mortality for the mother and her developing child. In the Netherlands this became more explicit after the publication of the PERISTAT (perinatal statistics) reports in 2008 and 2013 in which perinatal health indicators of 29 European countries were compared. The perinatal mortality rates of the Netherlands were relatively high in comparison to other high income countries [11]. This is felt by many to have resulted in a stricter use of national guidelines and more local protocols which can be seen as a process of re-evaluation of the boundaries of physiological birth. Scamel and Alaszewki describe this as an 'ever narrowing window of normality', in which normality is defined as the absence of risk [12]. Another

reason for the current risk discourse can be found in the increased scrutiny in maternity care, where bad outcomes can become subject to reviews, audits and medico-legal consequences. A policy focused on risk reduction, however, frequently leads to an increase in the number of interventions, including induction of labor, cesarean section, episiotomy, fetal heart rate monitoring during physiological birth, even hospital birth itself. All of these interventions naturally come with false positives (for instance "unneccesareans") [13]. As Bisits puts it: "Most of the risks in maternity care refer to low prevalence phenomena. Prevention or mitigation of these risks usually requires the treatment or management of large numbers of women in order to avoid an adverse outcome. This unavoidably results in over-treatment" [14 p.13]. The focus of risk discourse in maternity care, however, is usually on what numbers of overtreatment are acceptable when prevention of mortality or serious morbidity is at stake.

Some women feel like they are not being adequately counseled on the cost of a proposed intervention for the sake of risk minimization. Instead of numbers needed to treat, numbers needed to harm and exact incidences in percentages, they were informed by means of relative risks or odds ratios, concepts that are abstract and difficult to understand, even for health care providers themselves [15]. These women experienced a clash between differing risk perceptions, prompting some women in the current study to make a negative choice to leave the system. They indicated they needed an alternative for 'risk talk'. Risk talk as such cannot, and should not be completely avoided due to requirements of informed consent and informed choice, but midwives and other maternity care providers can use different techniques to put risk into perspective. It is important to realize that the way providers talk about risk and the strength of recommendations can be influenced by previous experiences and/or the dominant risk approach (culture) in the health institute of the maternity care professional [16]. Van Wagner suggested that risk talk of professionals can be prone to exaggeration [17]. As Scamel and Alaszewki state: "in midwifery conversation normality has no language of its own and has to be defined against the dominant discourse of high risk" [12 p.216].

Other women reject medical risk discourse altogether. They trust their instincts, believe that childbirth is a natural process and inherently safe, and locate risk in the interventions of caregivers [7,18]. These women sometimes make a positive choice to leave the system.

Respecting a woman's trust in the birth process and her autonomous choice

The second theme, "Need for autonomy and trust in the birth process", demonstrates that autonomy is a very important concept for most women who choose to go against medical advice in their birth choices. This is in accordance with previous studies, where this theme is frequently mentioned [19-25]. Autonomy in these studies included deciding how and where to give birth and who can be present at the event, and required full informed consent for every intervention. This even encompassed some minor or routine interventions by professionals, like taking a blood pressure, rupturing the membranes or performing an abdominal examination. If autonomy is overruled, this may lead to a traumatic experience and to women making a negative choice to leave the system. Full autonomy by necessity also means full responsibility. Many professionals believe that, because they have had substantial training and experience, and are authorized to make clinical decisions, they are responsible for not only the process, but also the outcome of a birth, for both mother and baby. However, women who choose to go against medical advice during birth feel that, if they made a fully informed choice, they themselves are ultimately responsible for the consequences of that choice, be they bad or good [25-27]. Some of these women even rejected the term "shared decision making", a concept that has become the current standard in counselling and informed decision in health care [28]. They felt that only one person could make a decision, and that should be them. However, shared decision making encompasses much more than provider and patient deciding on a course of action together. It also means involving patient preferences, background and culture in every decision on health needs, and has been shown to improve patient satisfaction in birth experience [29].

Most women in the current study expressed the need to be supported during birth by professionals and partners who, like them, trust in the birth process. They believed that if they were surrounded by professionals who saw birth as 'risky', that this could prove to be a self-fulfilling prophesy. Those present might, because of their perception of the inherent 'unsafety' of childbirth, be tempted to intervene in the natural process, thereby disturbing the flow of the birth and causing the very problems they were trying to prevent. As Wickham stated: "It may be uncomfortable to realise that 'we' can also be seen as an intervention, but if we can find ways of listening carefully to what this minority of women are saying we may be able to find ways of improving the experiences of all women" [30 p.5]. Recently Symon et al published a scoping review of this phenomenon of self-fulfilling prophesy described as the 'nocebo effect' [31]. He concluded that "it appears that nocebo is significantly more common in women and where there is prior negative knowledge/expectation (p.1526)."

In summary, it appears that women wish to be supported by someone who views and trusts birth as they do. For some this means: inherently safe if left alone. Also, in order to maximize their chances of an uncomplicated birth, they want to experience complete autonomy in all choices surrounding the birth. Ultimately this may mean also accepting final responsibility for the outcome for both themselves and their baby.

A flexible approach to negotiating the birth plan using the model of shared decision making

The third theme in the current study was "Conflict during negotiation of the birth plan". Feeley describes conflicts women experienced *after* making the *positive* choice for UC [6]. Conversely, in the current study, many women made a *negative* choice to leave the system *because* a conflict arose with their provider during the current pregnancy, or a previous one. This conflict frequently concerned their wishes for their birth plan.

Many women who ended up giving birth at home in a high risk pregnancy, or even unattended, started their current or previous pregnancy in regular care. Somewhere along the way a mismatch occurred between their childbirth wishes and the plan suggested by their provider. They experienced little or no shared decision making, but, in contrast, were confronted with "the protocol", deviation from which they found to be not open to discussion. Providers, on the one hand, have more extensive knowledge of the physiology and pathology of childbirth than most of their clients and use evidence based medicine to decide on a treatment plan. But they can also experience pressure from their institution and their colleagues to adhere to protocols and consider birth to be abnormal until proven otherwise [32-34]. This can appear as defensive medicine to some women. Participants in the current study feared that the policy suggested by their provider would prevent them from having the birth they wanted and would lead to more interventions, which would only worsen the outcome for them and their babies.

Birth plans are relatively new in maternity care. Introduced by childbirth educators in the nineteen-eighties in the United States, they became a way for women to defend themselves against the rising rate of interventions in US hospitals [35]. Jenkinson et al, in Australia, found that, among women who wanted to deviate from standard protocol, those who had a birth plan had more chance of achieving their desired birth [36]. On the other hand, Mei et al in the United States reported that the number of requests in a birth plan was inversely related to the level of patient satisfaction, unless those requests were honoured [37]. Unfortunately, rather than improving relationships, birth plans may irritate the staff, which adversely affects obstetric outcomes [35]. In other words, patients with birth plans are seen by medical personnel as "difficult", and almost setting

themselves up for disappointment. Debaets et al reported that many maternity care providers ignore birth plans because they feel they were made thoughtlessly and without prior discussion with the care provider themselves [38]. This made them recommend that patient and provider write the birth plan together, a variation of the concept of shared decision making. This irritation on the part of the caregiver was keenly felt by many participants in the current study, and was thought to have contributed to the conflict. Participants indicated that they experienced very little flexibility in their provider's attitude, and felt they had no other choice than to give birth elsewhere or with another provider. This is in accordance with a study by Keedle et al, who found that women who gave birth at home after a previous caesarean section did so due to inflexible hospital systems and inflexible attitudes [39]. These women found little or no support for their choice to attempt a VBAC in the regular system, or felt they had a better chance of a successful VBAC at home.

In summary, conflict over the birth plan caused by an experienced lack of flexibility from the provider may lead some women to make the choice to leave the system in the current or following pregnancy. If providers could recognize the "defining moment" and act on this, these negative choices might be prevented. This could perhaps be achieved by an open, empathetic attitude, negotiation using the concept of shared decision making, and an awareness that second best care (in the eyes of the provider) is a better alternative than a home birth for a high risk pregnancy, or no care at all.

Awareness of alternative delivery care providers and other sources of information

The theme "Search for alternative care" describes the women's search to find a care provider without fear, who will respect their autonomy, provide continuity of care and share their views on childbirth.

The last decade has yielded several studies -in different settings- on women's motivations for going against medical advice in their choices of place and provider for their delivery [5-7]. However, not much is known about how these women then proceed. Although most women in the current study decided on their own that they wanted to deviate from the medical protocol their provider had recommended, most did not reach their final decision without any outside influence. They became aware of alternatives to regular care by reading books, often written by natural childbirth advocates like Ina May Gaskin, Laura Shanley or Helene Vadeboncoeur [40-43]. The ideas of these authors were often quoted by the participants. They also took childbirth education classes, most often hypnobirthing. In accordance with the findings of Miller and Feeley, most if not all visited peer support websites dedicated to natural childbirth, unassisted

childbirth and home birth in a high risk pregnancy (for instance breech and/or VBAC), where they found information on the options available to them, and access to sympathetic midwives [6,20].

A perceived lack of continuity in care contributed to the participants' dissatisfaction and search for an alternative. The holistic midwives that were present at these high risk home births met that need. They performed all antenatal checks personally, and stayed with women who were in labor until the baby was born, even if a transfer to another setting became necessary. Dahlen et al likewise found that many participants in their qualitative study chose UC because of a lack of continuity in the hospital system [44]. They report that Australian women who opt for home birth or UC also found this continuity in doulas and (lay) midwives. In contrast to these findings, a recent structured literature review found that, in a general population, women wanted consistent care from caregivers that they trusted, but did not value continuity of carer for its own sake [45].

In summary, women in the current study searched for alternative information through books, internet or their social network, and often found a care provider who could deliver continuity of care(-r).

Maternity care without fear

Fear was the core category that united all themes in this study. Opting for a home birth in a high risk pregnancy or for UC is not an easy path and can be inspired by both positive and negative emotions [18]. Some of the participants in the current study were motivated by positive emotions. These women chose UC or home birth in a high risk pregnancy as a first choice, because, although they did not necessarily object to the presence of a midwife or hospital care in itself, they believed that such care had no added value in their situation. Other important ingredients for an optimal birth experience were an atmosphere of intimacy, relaxation, love and respect surrounding the birthing mother. Many participants felt that birth in such an atmosphere was a necessary requirement in order to become who they needed to be, "an empowered autonomous woman and mother" [25,46]. Others made a negative choice, where they had previous (or current) unsatisfactory experiences (in health care) and did not want to subject themselves to such care again. They chose a different setting for their delivery in order to avoid the alternative.

As Dahlen wrote recently: "Childbirth is no exception to this temptation to control through fear" [47 p.8]. Several of the participants in the current study mentioned 'shroud waving': their provider telling them they were risking the life of their child by making the choice for a home birth in a high risk pregnancy, or a UC. The participants felt this was not only indicative of coercion, but also of their

provider's fear of a bad outcome. The theme 'provider's fear' is also mentioned in literature. Plested et al interviewed ten women who had a UC in the United Kingdom [7]. They found that the fear of professionals for a bad outcome dominated medical discourse so much that participants felt burdened to the extent of withdrawing from care altogether. Jefford and Jomeen describe the effect of fear of a bad outcome on midwives working in the National Health Service in the UK [32]. They report how the midwives who were interviewed regularly felt they had to disregard their inclination to advocate for the rights of their birthing patients because of institutional policies and fear for their job or position.

Women's fear of medical professionals' interventions can also blind them to real risks involved in a UC or home birth in a high risk pregnancy. Dahlen in "Undone by fear? Deluded by trust?" describes two cases [48]. In one, a woman with two previous uncomplicated births died after having an elective caesarean section for a breech position. She was undone by fear. Her counterpart, a vocal Australian UC advocate, died during an unassisted home birth. She was deluded by trust. The author argues that both unmitigated fear (implied: imposed by professionals), as well as unconditional trust in the natural course of childbirth can lead to a bad outcome. This unconditional trust was certainly voiced by some of the participants in the current study. They believed that most if not all medical interventions are unnecessary and will only cause a cascade of further interventions, leading to a bad outcome. For instance, several of the participants believed that shoulder dystocia and post partum haemorrhage do not occur in unassisted childbirth and are always due to providers' interventions.

In summary, the participants in this study described two dimensions of fear: their own fear of a cascade of unnecessary interventions, and their provider's fear of a bad outcome and the repercussions thereof.

Implications for practice: preventing high risk choices for negative reasons

This study demonstrates that some women choose a home birth in a high risk pregnancy or a UC as a positive first choice, whereas others do so out of negative associations with maternity care. New insights generated by this study highlight the negotiation and conflict surrounding the birth plan, and the search for alternative care. Many caregivers feel frustrated and concerned for both the mother and the baby's welfare when confronted with a pregnant patient who refuses routine care or even any care at all. They wonder how they can get the patient to comply with medical advice. But perhaps this is the wrong approach in these situations. If the woman's choice is a positive one, it seems there is little or nothing a caregiver can do or offer that will make her change her mind. However, if the choice is negative, there is a reason why a woman is choosing to

avoid certain measures that are offered to her, and we should be asking her why. As this study shows, many women who reject medical advice have been traumatized during a previous birth, where they felt left alone, not taken seriously, or even violated. The women in this study felt that in hindsight certain interventions done to them in the past were unnecessary, or even harmful. They felt they were not properly informed and did not give full informed consent.

If we as health care professionals wish to prevent women from making what we consider high risk choices for negative reasons, there is much to be gained from preventing traumatic experiences. We must face that in daily practice difficult situations can arise when evidence based medical knowledge clashes with women's views. However, in this time of increasing use of shared decision making and a growing awareness of the importance of patient relevant outcomes such as patient satisfaction with care [49], new ethics are required in maternity care. Equal partnership between care provider and pregnant woman is a prerequisite for a transparent dialogue, where counselling is done without coercion and with full disclosure of all known facts. These facts should be presented as absolute risks, numbers needed to treat and numbers needed to harm, and clear information should be given about what is not actually known. Threats and "shroud waiving" should be avoided and informed consent is required for any and all interventions. Furthermore, an attempt should be made to minimize changes in caregiver, thereby increasing continuity of care. If it becomes clear the woman persists in her high risk choice, she should be told that she will always be welcome in "regular" maternity care if she changes her mind or if complications arise.

There will always be some women who make a positive choice to take a different route, but negative choices are undesirable for both women and providers. The main goal of counselling should not be to bring as many women as possible within the framework of protocols or guidelines, but to prevent negative choices.

Strengths and limitations

All authors are or were involved in maternity care and are committed to the improvement of birth outcomes. The interviewers were familiar with the Dutch maternity system. This background is visible in the topic list and the importance assigned to the results regarding women's autonomy, although autonomy is an important theme in all the international literature on this subject. Participants were aware that interviewers, as medical professionals, were (formerly) part of the 'system' which they critiqued. It is possible that for some this led to a certain reticence in answering freely. On the other hand, the medical background of the interviewers made it possible to quickly discern which questions were relevant to ask.

There are several strengths to this study. First, for a qualitative study, it is extensive, with in-depths interviews with 28 women, from different socio-economic backgrounds. Second, whereas most qualitative health research uses an abbreviated grounded theory, in this study the full iterative cycle was performed: after 10 interviews a preliminary data analysis took place, on the basis of which the topic list was improved, the researchers returned to the field and new interviews were undertaken until data saturation was achieved. Third, it is the first such study to be done in the Netherlands, with a maternity system known for its physiological approach to childbirth and its general acceptance among both public and professionals of home birth as a regular option for healthy women with a physiological pregnancy. Fourth, it is part of the larger WONDER-study project, from which two literature studies have already been published [2,5]. Triangulation between the results of literature studies and the data analysis of the interviews has heightened the validity of this research.

Another strength of the study is its critical reflection on validity, by having a feedback focus group discussion with a representative sample of the study population.

Naturally, there are also limitations to this study. First, one could assume that because this study was performed in the specific setting of Dutch maternity care, the results are not necessarily applicable to other countries and healthcare systems. However, the phenomenon of 'birthing outside the system' is not specific for the Netherlands, and most of the themes that were found in this research are in accordance with findings from other studies elsewhere. Second, the sampling method can be seen as a limitation. There is no formal registration of women who go against advice in choosing their method and/or place of birth, therefore interviewers had to rely on snowball methods and internet fora. It is possible that participants with activist views on home birth in a high risk pregnancy and UC are over represented. The researchers actively searched for negative cases of women who regretted their choice, but could not find any. Moreover, it seems safe to assume, that for every woman who chooses to go against medical advice, there are likely many who have similar misgivings, but opt, for various reasons, to stay within the system. This should be a focus for future research.

Conclusion

This qualitative study analyzed the motivations of Dutch women who chose home birth in a high risk pregnancy or unassisted childbirth, against medical advice. Four major themes were found: 1) Discrepancy in the definition of superior knowledge, 2) Need for autonomy and trust in the birth process, 3) Conflict during negotiation of the birth plan, and 4) Search for different care. This study shows that, even though maternity care in the Netherlands has, in comparison to other developed countries, a low rate of interventions and a relatively high home birth rate, some of the themes mentioned by Dutch women as motivation for choosing to go against medical advice are similar to those found in studies elsewhere.

From the data one theme emerged that covered all of the other themes and this was 'Fear'. This theme refers both to the participants' fear (of interventions and negative consequences of their choices) and to the providers' fear (of a bad outcome). Where for some women it was a positive choice, for the majority of women in this study the choice for a home birth in a high risk pregnancy or a UC was a negative one.

Recommendations for maternity caregivers can be summarized as: 1) Rethink risk discourse, 2) Respect a woman's trust in the birth process and her autonomous choice, 3) Have a flexible approach to negotiating the birth plan using the concept of shared decision making 4) Be aware of alternative delivery care providers and other sources of information used by women, and 5) Provide maternity care without spreading or using fear.

References

1) Christiaens W, Nieuwenhuijze MJ, de Vries R. Trends in the medicalisation of childbirth in Flanders and the Netherlands. Midwifery 2013 Jan;29(1):e1-8.
2) Hollander M, van Dillen J, Lagro-Janssen T, van Leeuwen E, Duijst W, Vandenbussche F. Women refusing standard obstetric care: maternal-fetal conflict or doctor-patient conflict? J Preg Child Health 2016; 3:2.
3) Cherry A. The detention, confinement, and incarceration of pregnant women for the benefit of fetal Health. J. Gender & L. 2007;16:147.
4) Hickman A. Born (not so) free: legal limits on the practice of unassisted childbirth or freebirthing in the United States. Univ Minn Law Rev 2010;94:5.
5) Holten L, de Miranda E. Women's motivations for having unassisted childbirth or high-risk home birth: An exploration of the literature on 'birthing outside the system'. Midwifery 2016;38:55–62.
6) Feeley C, Thomson G. Why do some women choose to freebirth in the UK? An interpretative phenomenological study. BMC Pregnancy and Childbirth 2016;16:59.
7) Plested M, Kirkham M. Risk and fear in the lived experience of birth without a midwife. Midwifery 2016; Jul;38:29-34.
8) Offerhaus PM, Geerts C, de Jonge A, Hukkelhoven CW, Twisk JW, Lagro-Janssen AL. Variation in referrals to secondary obstetrician-led care among primary midwifery care practices in the Netherlands: a nationwide cohort study. BMC Pregnancy Childbirth. 2015 Feb 21;15:42.
9) Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19(6):349–357.
10) Charmaz K. Constructing grounded theory. A practical guide through qualitative analysis. 2nd ed. London: Sage publications; 2007.
11) Peristat. http://www.europeristat.com/reports/national-perinatal-health-reports.html.
12) Scamell M, Alaszewski A. Fateful moments and the categorisation of risk: Midwifery practice and the ever-narrowing window of normality during childbirth. Health, Risk &Society 2012;14(2): 207-221.
13) http://www.theunnecesarean.com.
14) Bisits A. Risk in obstetrics-Perspectives and reflections. Midwifery 2016;38:12-13.
15) Martyn C. Risky business: doctors' understanding of statistics. BMJ : 2014;349.
16) Pel M, Heres MH, Hart AA, van der Veen F, Treffers PE. Provider-associated factors in obstetric interventions. Eur J Obstet Gynecol Reprod Biol. 1995 Aug;61(2):129-34.
17) Van Wagner V. Risk talk: using evidence without increasing fear. Midwifery 2016;38:21-28.
18) Chadwick RJ, Foster D. Negotiating risky bodies: childbirth and negotiations of risk. Health, risk & Society 2013; Vol. 00, No. 00, 1–16.
19) Feeley, C, Burns, E, Adams, E, Thomson, G. Why do some women choose to freebirth? A meta-thematic synthesis, part one. Evidence Based Midwifery 2015;13:4–9.
20) Miller, A. Midwife to myself: Birth narratives among women choosing unassisted home birth. Sociological Inquiry 2009;79:51–74.
21) Lindgren H, Radestad I, Christensson K, Wally-Bystrom K, Hildingsson I. Perceptions of risk and risk management among 735 women who opted for a home birth. Midwifery 2010;26:163–172.
22) Viisainen K. Negotiating control and meaning: home birth as a self- constructed choice in Finland. Social Sci Med 2001;52(7):1109–1121.
23) Boucher D, Bennett C, McFarlin B, Freeze R. Staying home to give birth: Why women in the United States choose home birth. Journal of Midwifery & Women's Health 2009;54:119–126.
24) Murray-Davis B, McNiven P, McDonald H, Malott A, Elarar L, Hutton E. Why home birth? A qualitative study exploring women's decision making about place of birth in two Canadian provinces. Midwifery 2012;28:576–581.

25) Freeze R. Born free: Unassisted child birth in North America (Thesis). University of Iowa, written 2008, retrieved April 22 2015. (http://ir.uiowa.edu/cgi/viewcontent.cgi?article¼1387&-context¼etd)
26) Symon A, Winter C, Donnan P, Kirkham M. Examining autonomy's boundaries: a follow up review of perinatal mortality cases in UK independent midwifery. Birth 2010;37:280–287.
27) King J, Moulton B. Rethinking informed consent: the case for shared medical decision-making. Am J Law Med. 2006; 32(4): 429-501.
28) Nieuwenhuijze MJ, Korstjens I, de Jonge A, de Vries R, Lagro-Janssen A. On speaking terms: a Delphi study on shared decision-making in maternity care. BMC pregnancy and childbirth. 2014;14(1):223.
29) Cameron H. Expert on her own body: contested framings of risk and expertise in discourses on unassisted childbirth (Thesis). Lakehead University, Retrieved April22 2015. (http://thesis.lakeheadu.ca:8080/bitstream/handle/2453/526/CameronH2012m-1a.pdf?sequence¼1)
30) Wickham S. Unassisted birth: listening and learning from the minority. Practising Midwife 2008;11:4–5.
31) Symon A, Williams B, Adelasoye QA, Cheyne H. Nocebo and the potential harm of 'high risk' labelling: a scoping review. J Adv Nurs. 2015;71(7):1518-29.
32) Jefford E, Jomeen J. "Midwifery abdication": a finding from an interpretive study. Int J Childbirth 2015;5(3):116-125.
33) Healy S, Humphreys E, Kennedy C. Midwives' and obstetricians' perceptions of risk and its impact on clinical practice and decision-making in labour: An integrative review. Women Birth. 2016 Apr;29(2):107-16.
34) Henshall C, Taylor B, Kenyon S. A systematic review to examine the evidence regarding discussions by midwives, with women, around their options for where to give birth. BMC Pregnancy Childbirth. 2016 Mar 14;16:53.
35) Lothian J. Birth plans: the good, the bad, and the future. J Obstet Gynecol Neonatal Nurs. 2006;35(2):295-303.
36) Jenkinson B, Kruske S, Stapleton H, Beckmann M, Reynolds M, Kildea S. Maternity care plans: A retrospective review of a process aiming to support women who decline standard care. Women and Birth 2015;28:303–309.
37) Mei JY, Afshar Y, Gregory KD, Kilpatrick SJ, Esakoff TF. Birth plans: What matters for birth experience satisfaction. Birth 2016;43(2):144-50.
38) DeBaets AM. From birth plan to birth partnership: enhancing communication in childbirth. Am J Obstet Gynecol. 2017 Jan;216(1):31.e1-31.e4.
39) Keedle H, Schmied V, Burns E, Dahlen HG. Women's reasons for, and experience of, choosing a home birth following a caesarean section. BMC Pregnancy and Childbirth 2015;15:206.
40) Gaskin IM. Spiritual Midwifery 4th revised ed. 2002. Book Company Publishing.
41) Gaskin IM. Ina May's Guide to Childbirth. 2008. Ebury Publishing.
42) Shanley LK. Unassisted Childbirth. 3rd Ed. 2016. Bergin & Garvey.
43) Vadeboncoeur H. Birthing normally after a caesarean or two. 2011. Fresh Heart Publishing.
44) Dahlen HG, Jackson M, Stevens J. Home birth, freebirth and doulas: casualties and consequences of a broken system. Women and birth 2011;24(1):47-50.
45) Green JM, Renfrew MJ, Curtis PA. Continuity of carer: what matters to women? A review of the evidence. Midwifery 2000; 16: 186-196.
46) Cheyney M. Home birth as systems-challenging praxis: knowledge, power, and intimacy in the birthplace. Qualitative Health Research 2008;18:254–267.
47) Dahlen HG. The politicisation of risk. Midwifery 2016;38:6-8.
48) Dahlen H. Undone by fear? Deluded by trust? Midwifery 2010;26:156-162.
49) Porter ME, Olmsted Teisber E. Redefining Health Care. 2006. Harvard Business Review Press.

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Fulfilling a need. Holistic midwifery in the Netherlands: a qualitative analysis

Submitted
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Abstract

Background

The Netherlands has a maternity care system with integrated midwifery care including the option of home birth for all low risk women. A small group of Dutch (holistic) midwives is willing to assist women in high risk pregnancies during a home birth against medical advice. There are no qualitative studies on holistic midwifery in the Netherlands yet. We examined holistic midwives' motivations and way of practice, in order to provide other maternity care professionals with insight into the way they work and to improve professional relationships between all care providers in the field.

Methods

An exploratory qualitative research design with a constructivist approach and a grounded theory method were used. In-depth interviews were performed with twenty-four holistic midwives on their motivations for working outside their professional boundaries. Open, axial and selective coding of the interview data was done in order to generate themes. A focus group was held for a member check of the findings.

Results

Four main themes were found: 1) The regular system is failing women, 2) The relationship as basis for empowerment, 3) Delivering client centered care in the current system is demanding, and 4) Future directions. One core theme emerged that covered all other themes: Addressing a need. Holistic midwives explained that many of their clients had no other choice than to choose a home birth in a high risk pregnancy because they felt let down by the regular system of maternity care. They wanted to address this need, sometimes at high personal and professional cost.

Conclusions

Holistic midwives appear to deliver an important service. They provide continuity of care and succeed in establishing a relationship with their clients built on trust and mutual respect, truly putting their clients' needs first. Some women feel let down by the regular system, and holistic midwives may be the last resort before those women choose to deliver unattended by any medical professional. Maternity care providers should attempt to understand and meet the needs of all pregnant women, and should consider working with holistic midwives in the interest of good patient care.

Background

In the Netherlands, midwives can work in several settings and functions. The majority (72%) work as community midwives in primary care. The other 28% work as clinical midwives in hospitals, under supervision of an obstetrician [1]. Most of the community midwives work in group practices (80%), with an average size of four to six midwives, who together provide care for approximately 90 women per midwife per year. They share antenatal check-ups and on calls, so their clients see most or all midwives in the practice in turn. Around 15% of community midwives practice as a duo and 5% work in a solo practice [1].

In recent years, case-load midwifery has made an appearance in the Netherlands. Case-load midwifery is defined as a (community) midwife who accepts a limited number of clients per month (four to five is average), for whom she is the only care provider. This means she personally (with a few exceptions for holidays or illnesses) performs all antenatal checks and also attends the birth herself. In a duo or group of case-load midwives, sometimes two midwives take turns being on call for their combined clientele. Some of the hallmarks of case-load midwifery are continuity of care, a holistic (multidimensional) approach to pregnancy and childbirth, extra time spent per woman, and a personal relationship with the client [2].

Community midwives in the Netherlands provide complete antenatal, natal and postnatal care to women with a low risk pregnancy. Women with a high risk pregnancy, or those who become so, are referred to hospitals for secondary (specialized) care, either during pregnancy, childbirth or postpartum, where they are attended by (trainee) obstetricians and/or clinical midwives working under an obstetrician. Half of the women who give birth in the care of a community midwife do so at home, the other half in a hospital or birthing center. Approximately 43% of women who started labour under supervision of the midwife are referred to secondary care during or immediately after childbirth [3]. However, there is a perception among maternity care providers that an increasing number of women refuse to be referred. They opt for a home birth in a high risk pregnancy with a midwife present. This 'birthing outside the system' includes, among other indications, post term pregnancies, twin pregnancies, breech births and vaginal births after previous caesarean section (VBAC). Midwives are not supposed to supervise these births at home, as this is in conflict with official guidelines and agreements between professionals. Therefore, the vast majority of community midwives does not want to take responsibility for those births. A small number of midwives (mostly working case-load) have stepped forward and are willing to assist women, who refuse the recommended (hospital) care, with a planned home birth. We will from here

on refer to these midwives as "holistic", since this is the term used most frequently in literature [4,5] .

In 2014, a highly publicized court case took place, in which charges were brought by the Health Inspection against three holistic midwives for assisting during home births involving twins and breech births [6]. After final review at appeal, the court recognized the fact that these midwives were the only assistance some women would accept during childbirth, and that any assistance was better than none. They were therefore acquitted, although one was penalized for not making sufficient case notes to substantiate why she was in attendance, and for performing inadequate resuscitation on a neonate. The court further stipulated that birthing women should not be left alone (by their caregiver) against their wishes, even if this means that the midwife has to attend a high risk birth at home.

Prompted by this court case, the WONDER-study (Why women want Other or No DElivery caRe) was conceived in order to gain more insight in the phenomenon of women refusing recommended (hospital) care and opting for a home birth in a high risk pregnancy. The WONDER-study is a mixed methods study examining women's motivations to choose home birth in a high risk pregnancy or unassisted childbirth (UC), the motivations of their caregivers to assist them, and explores the magnitude of birthing 'outside the system' as perceived by midwives and gynaecologists, as well as their opinion on this phenomenon [7-10].

In most developed countries, home births attended by midwives are relatively rare and are generally considered by the medical establishment as 'against medical advice' [11]. Most births take place in hospitals, and if women refuse recommended care, midwives usually 'side with' the obstetricians in trying to persuade women to go along with the advice [12,13]. In contrast to the situation in the Netherlands, where home birth for low risk women is still considered a regular choice within standard maternity care, home birth midwives elsewhere generally do not distinguish between low and high risk births in a system where birth in itself is considered high risk [14]. In a country known for its physiological approach to childbirth, relatively low intervention rates and high percentage of home births, it might seem strange that there is an apparent need for holistic midwives. In order to elucidate this matter, we interviewed the majority of holistic midwives in the Netherlands, who are willing to accept women with a high risk pregnancy for home birth, on their motivation to work the way they do, on how they feel about Dutch maternity care and on what distinguishes the way they practice from regular community midwives.

Methods

Describing data analysis and reporting of the findings was done using the Coreq criteria for qualitative research [15]. Permission to perform this study was sought from the medical ethics committees of the Radboud University Medical Center Nijmegen and the Academic Medical Center in Amsterdam, who both judged that the study did not require ethical approval.

Research team

All interviews were conducted by either MH, EdM or LH, who are all women and professionals with a background in midwifery/obstetrics. All had experience with conducting interviews, and one (LH) had had previous interviewing experience during her PhD studies in medical anthropology. All interviewers had a professional interest in organization of maternity care in general and the phenomenon of home birth in high risk pregnancies specifically. Some of the participants were known to the interviewers through conferences, workshops, professional networks or social media, but only one participant had had professional contact with one of the interviewers (MH) through a shared case.

Study design

This qualitative research study uses a constructivist and phenomenological approach and an abbreviated grounded theory method and analysis [16]. Participants were selected predominantly through a purposive sampling method: two of the midwives involved in the court cases mentioned above were approached. In addition, all Dutch midwives known to the researchers to be practicing in a holistic setting and known to be prepared to assist women with home birth in a high risk pregnancy were asked to participate. Finally, a snowball method was used, by which all participants were asked if they knew of any colleagues working similarly. These were then also requested to participate. All participants were approached by either e-mail or private message on a social media platform. In total, 28 midwives were approached, which, according to those interviewed, represent the vast majority of holistic midwives working in the Netherlands at the time. Four midwives refused to participate. Reasons for refusal were cited as "Uncertainty about the agenda of the study group", "Not trusting confidentiality" and "Lack of time".

All interviews took place in a location chosen by the participants, which was most often either in their home or place of work, and rarely in a public place like a café. One interview was done by telephone, due to logistical reasons. All conversations took place in private. Data were collected between the summer

of 2014 and the spring of 2016 and all participants gave verbal consent for their quotes to be used in this article.

The interviews were semi-structured by use of a topic list (Figure 1), which was based on questions the researchers had after studying the literature at the

Figure 1 Topic List

Experience: What is your experience with delivering care outside guidelines? What motivates you to be prepared to deliver this care? Do you think these requests are increasing? If so, why? How long have you worked as a midwife? Where were you trained? How would you describe yourself, in your role? Which high risk situations have you encountered in your practice?
Practice: Can you describe your practice? (solo, case load, duo, group etc) How many women do you see? If case load, do you charge extra? How would you describe the women that come to you? How far will you travel for a birth?
Network: How do clients find you? Do you have a back-up midwife? Do you have an agreement/understanding with a (local) hospital? Are you part of the local organization for maternity carers? What is your network like? How would you describe your contacts with other (regular) carers?
Values: What is a good birth? What is a bad birth? What do you expect from a client? What makes a good provider? What is your opinion on "alternative midwives"? Do you have any religious views?
Trust: Do you have confidence in Dutch maternity care? In science/EBM/protocols/guidelines? In your training? What do you do to gain/keep a client's trust?
Guidelines: What is the role of guidelines for you, for doing your job? (positive/negative) Do ideas about medicalization play a role in the way you practice?
Preparation: How do you prepare for a birth outside guidelines? Do you take precautions? Extra time talking to the client? Extra notes? Talk to colleagues? Do you make clients sign anything (legal)? Do you have boundaries? Where are they?
Risk perception: How do you weigh risks around high risk (home-) births? What makes you decide to accept a request?
Power: Do you ever comply with guidelines when you really want to deviate? Why? How do you communicate with obstetricians? (Are you prepared to make a stand for your client?) How do you feel the power balance between you and your client?
Fear: Do you experience birth outside guidelines differently? Were you scared? (of a bad outcome, your reputation, legal repercussions)
Legal issues: Have you ever had a problem with the Health Inspection? Have you ever had a bad outcome? If so, how did you deal with this? Do you have liability insurance?
Autonomy: How do your ideas on autonomy factor into this story? (autonomy of the mother vs the interests of the child)
Ideal maternity care: If there were one thing you could alter in Dutch maternity care, what would it be? Do you have a mission? Do you have any advice for other maternity carers?

start of the study, and this was adjusted throughout the study as new themes were brought forward by the participants. The interviews were allowed to take a spontaneous course, and lasted between 45 and 150 minutes. Most midwives were interviewed once, with two having had two separate sessions. Interviews were recorded by digital sound recorder and transcribed verbatim by either a commercial company or volunteer medical students. All sound files and transcripts were stored anonymously in a secured password protected university digital storage system.

In September of 2016, a feedback focus group was held with six of the participants, four of whom were physically present, and two were on speaker-phone.

The first author (MH) translated all quotes into English.

Data analysis

Data were analyzed by the first author (MH), with LH coding one interview halfway through the process to check for any missing codes. Qualitative data analysis software program MaxQDA (VERBI GmbH) was used for the coding process. Open coding was started from the bottom up, with codes being added and expanded on as new interviews were coded. Codes were grouped in themes and subthemes, after which a core category emerged. Data saturation was reached after 21 interviews, with the final three interviews being coded to confirm this. The codes were grouped into the final coding tree (Figure 2), which was decided on by consensus between LH and MH after all coding had been completed.

Results

Twenty-four midwives were interviewed. The majority (66.6%) of participants practiced case-load midwifery. Sometimes as a solo practitioner, sometimes in a group or duo (Table 1). Three midwives worked in a regular group practice, in which clients were shared. These individual midwives were willing to assist women, who refuse the recommended (hospital) care, with a planned home birth. The average age of participants was between 40 and 50 years old, and they had been practicing midwifery for an average of fourteen years, with a range of two to thirty years. The first participant who started a holistic case-load practice did so around the year 2000, and most have been working this way for less than ten years. Fourteen midwives (58.3%) worked in an urban setting.

After grounded theory analysis of all interviews four major themes emerged: "The regular system is failing women", "The relationship as basis for empowerment",

"Delivering client centered care in the current system is demanding" and "Future directions". After careful consideration of all data, it became clear that one overarching core theme connected all other themes and subthemes. This core theme was "Addressing a need". Six participants took part in the feedback focus group. All agreed that the results were a fair representation of their stories, however, they all felt that there needed to be more emphasis on their physiological approach to childbirth. We incorporated these remarks in the emphasis we have placed on certain themes. While organizing the feedback focus group, 18 months to three years after the interviews, we reconnected with as many participants as we could, and found that nine of the 24 were no longer in practice, or at least not as holistic midwives. Of the fifteen midwives who were still active in their holistic practice, two were currently trying to decide if they want to keep working in that setting.

Table 1 Characteristics of the participants

Age	21-30	1	(4.2%)
	31-40	9	(37.5%)
	41-50	10	(41.7%)
	51-60	4	(16.7%)
Work experience	0-10 years	9	(37.5%)
	11-20 years	10	(41.7%)
	21-30 years	5	(20.8%)
Average	14.2 years		
Practice	Urban	14	(58.3%)
	Semi-rural	4	(16.7%)
	Rural	6	(25.0%)
Work setting	Solo		
	Case load	12	(50.0%)
	Non case load	2	(8.3%)
	Duo		
	Case load	1	(4.2%)
	Non case load	2	(8.3%)
	Group		
	Case load	3	(12.5%)
	Non case load	3	(12.5%)
	Locum	1	(4.2%)

The regular system is failing women

An important motivation for participants to accept women with a high risk pregnancy for home birth, is their conviction that the regular maternity care system in the Netherlands is failing women. They feel that there is too much emphasis on risk talk, and not enough room for a physiological approach to childbirth. Participants believe that the regular system relies too much on protocols, at the expense of patient centered care, and lacks time, attention, and continuity. They stress that frequent use of a paternalistic approach and lack of informed consent traumatizes women.

All participants describe the current biomedical discourse and reliance on protocollized care as too dominant. They point out that, although evidence based medicine (EBM) is an improvement to authority based medicine, it is often used in too limited a sense. One of the cornerstones of EBM is patient preference, which they feel is not taken into account often enough, in the presence of protocols which provide strong recommendations:

> *"It is everywhere in all the guidelines […]: the client comes first. I don't think the client comes first, I think the guidelines come first. And they are no longer guidelines, they have become laws." (Midwife 20)*

The participants felt that due to the increase of protocols recommending interventions, women have less options to have an intervention-free birth:

> *"Because I wouldn't want to be there, in that setting. With everything they have, you know… […] one is ready with the syringe, the other with the vacuum, the third with an iv. […] That is war, instead of cooperating with the forces of nature and the woman's power." (Midwife 6)*

Participants also describe maternity care providers' (both doctors' and midwives') fear of litigation tends to make them overly cautious, whereby they would rather do too much than too little:

> *"I believe that maternity care as it is now is going in the wrong direction, because I feel like… [colleague] said it very well: 'People would rather be judged for the things they did than for the things they didn't do', that we are almost headed for an American system, that we all try to rule out as many risks as possible […] with the idea: at least we tried everything." (Midwife 21)*

When asked why women approached them, most participants stated that the current maternity care system does not give women an honest chance of a normal birth.

> *"It's just like: this is how it's done, this is how the infusor is adjusted, this is how the CTG is done and this is how long you are allowed to push and you should do it in such and such a way… So it becomes, yes, it becomes almost a little bit like a factory." (Midwife 9)*

Participants also complained about lack of time and continuity in regular maternity care. Women are confronted with many different providers, who have very little time to spend per consultation.

> *"Colleagues [regular midwives] would say: 'You give patients so much time, soon they will want the same from us, we can't do that, we don't have the time for it!' So you are just in a [group] practice where you see six people in an hour and when someone says: 'I am so afraid of giving birth!' then you say: 'I have three minutes to talk about it', or, 'Don't worry about it. You have us! You will be fine!'" (Midwife 21)*

Participants reported that one of the most important reasons women come to them, is because many have been traumatized in regular care, often due to loss of autonomy.

> *"When the woman was not heard, , when decisions have been made without consulting her, […] when doctors come in and….when they go like this with two fingers and immediately go for your vagina instead of shaking your hand first, you know, I find that really excruciating." (Midwife 21)*

According to many participants, maternity care is still a very paternalistic field, in which women are frequently coerced and informed consent is optional. When women refuse certain parts of the protocol, there is no flexibility and no concessions are made, leading the women to take extra risks by approaching holistic midwives for home birth assistance in high risk pregnancies:

> *"And there was a lady who would have been willing to mostly conform to the guidelines, but the door was slammed in her face. I think based on the conviction, that if you just keep saying no, then….. Like with a child, if we just keep saying no, at some point they will accept it [that they have to follow protocol]" (Midwife 7)*

"For instance intermittent auscultation in a vaginal birth after Cesarean, instead of continuous monitoring. That was […] not done. I dragged her to six hospitals in our area, and everywhere we were told no. Until the lady said: 'Then I will stick with my decision, I will birth at home.'" (Midwife 18)

Figure 2 Code Tree

CORE THEME: ADDRESSING A NEED

The regular system is failing women

- Scientific approach, weighing risks and benefits
  - Exaggerated risk perception
    . Risk to the baby
  - Limits to evidence based medicine
- They don't give women/normal birth a chance
  - Increase in protocols
  - Lack of flexibility
  - Not enough time and attention for women as individuals
  - They don't listen to women
  - Paternalistic treatment of women in the regular system
  - Women are traumatized
    . Own birth experience
  - No continuity of care

The relationship as basis for empowerment

- Putting the client first
- Individualized care without fear
  - Feeling safe
- Intuitive approach, complimentary approach, bodywork
  - Intuition
  - The beauty of birth
- Making time, listening, continuity of care
- Trust in the relationship between client and midwife
- The client decides
  - Honesty
  - Complete informed consent

Delivering client centered care in the current system is demanding

- Difficult to work with regular (hospital) carers
  - Inexperienced trainees

Figure 2 Continued

- Connections with other likeminded caregivers
  - In primary care
  - In secondary care
    . Being open about what you are doing
  - Social media
- You have to be well prepared
  - Thinking about your role
  - Personal skills, feeling capable
  - Impeccable paperwork
- Working caseload
  - Indications
  - Travel limits
  - Limited client base, always on call
  - Financial restraints
- Fear
  - Dealing with a bad outcome
  - Threats and coercion, legal ramifications
    . Secrecy

Future directions

- Hospitals should honor informed consent and SDM
- More flexibility and continuity in the regular system
- Creative solutions
- Working from within the system to improve the situation

The relationship as basis for empowerment

The midwives who participated in this study have a different and personal approach to maternity care compared to the regular system. Building a trusting relationship with their clients is at the core of their work. This means that there has to be a personal connection between midwife and client, which serves to empower the client to take responsibility for her own process:

> *"If a client approaches me the first thing I ask myself [about her] is: can you carry yourself? Are you […] prepared to deal with your process and reflect on it? And are we capable of establishing a meaningful relationship?" (Midwife 8)*

Holistic midwives want to deliver individualized care without fear. They believe decisions in maternity care should be made based on the individual woman, her experiences and her preferences, not taken directly from any guideline or study.

They may treat the guidelines as a starting point for negotiations, but some discuss all possible options, also those not recommended in the guidelines:

> *"Yes. I go along with every wish. If I feel like people are actually taking responsibility for it themselves. I have to feel like they have thought it through sufficiently. That they are coming from a position of strength and not from fear. For instance, not from fear of ending up in a hospital, but from a conviction or a trust in something: in themselves, or whatever. I have to feel like they can carry themselves. If not, I won't do it." (Midwife 4)*

Participants believe that honesty and trust in the relationship are prerequisites for going outside the boundaries of the protocols:

> *"The rest is all about talking to each other to determine if we can trust each other. […] That is what the whole care is about. If there was something not right or something didn't fit, that would be a reason for me to evaluate: am I still the right caregiver for you?" (Midwife 17)*

Some women are so set against going to the hospital that they are almost impossible to persuade to be referred. However, the majority of participants find willingness to be referred an important condition for their partnership with their clients. If the midwife feels that that trust is lacking, she may not be prepared to go forward in her role as caregiver:

> *"When we get to this point, that means there is something in our mutual confidence that is not right. At first I failed to get the conversation to that level. I thought: I don't want it this way. First the foundation has to be right, then we can move on." (Midwife 24)*

Long consultations, listening to women's needs and continuity of care are the hallmark of case-load midwifery, as practiced by the majority of the participants. They frequently see their clients for an hour or more each time, and they are usually the only midwife their clients see. This builds the trust necessary for clients to be willing to follow the midwife's advice in case of a need for referral during the birth:

> *"Probably because you see each other again and again […] women say: 'If you say that there is a limit, I will completely follow you.' They dare to put it in your hands, while before they were afraid to put it in anyone's hands, because you have spoken a lot and because they know I take them seriously." (Midwife 14)*

Some participants who worked in a regular group practice experienced a lack of opportunity to build such trust with the majority of their clients, since they did not have enough time to get to know the them:

> *"I have noticed, for instance, now that we are four [midwives], some women I see once, twice in the pregnancy. I don't build a relationship with those anymore." (Midwife 22)*

The majority of participants believe that going outside protocol should always be at the client's suggestion, and the client should always have the final say in every decision:

> *"What do I do in my job? I listen to what people want. And it is nice that we have standards, guidelines, rules and what not, but the most important thing is: what does the woman want?" (Midwife 11)*

However, not all participants counsel their clients with complete neutrality on all options. Some do allow their own opinions to occasionally guide their advice to their clients, or steer them in a certain direction. In some cases that may lead the midwife to perform less check-ups and interventions than are recommended, because of her personal opinion about these interventions:

> *"If someone is birthing in the bath, in a natural position, and is pushing without being coached, I don't find it necessary to listen (to the heartbeat) quite so often, and I determine that for that woman." (Midwife 15)*

A minority of participants has a more intuitive approach to their work. Some practice complimentary techniques such as homeopathy, herbal remedies and massaging techniques. During their work they are often guided by their own as well as the mother's intuition in judging fetal condition or labor progression. They see birth not as a medical occurrence, but as something the female body was made for:

> *"That decision that I want to follow my heart has been a very important choice. My heart was my guideline, you see, not the protocol or the rules, but just my heart and my intuition." (Midwife 6)*

Delivering client centered care in the current system is demanding

Being prepared to accept women with a high risk pregnancy for home birth and working (mostly) case-load is often rewarding for these midwives, but frequently also a heavy burden. Participants feel stigmatized or even villified by regular maternity care providers, and are made to fear legal repercussions in case of a bad outcome, which makes working the way they do emotionally difficult. They spend much time preparing and planning for a particular birth, and most try to be open about what they are doing. Most participants are almost always available for their clients, for little financial reward, and sometimes have to travel far outside their own region.

One of the things that participants have the most difficulty with is their working relationship with regular providers; sometimes community midwives, mostly obstetricians (and trainees) in hospitals:

> *"But there are also midwifery practices who don't want to be [my] back-up and then I just don't have…a back-up. Because then no-one in the whole area wants to be [my] back-up and that is the end of it. Then it is just a longer drive. So what I discuss with the client is that the hospital is basically the back-up at such times and that in case of an acute emergency she should just…call the ambulance. That, in my opinion, does not constitute the best care, but it is what it is." (Midwife 4)*

> *"In the eleven years I have worked I have been told off by an obstetrician and I have been ignored many times. There are obstetricians who still ignore me. I always find that very intimidating and I let myself be intimidated." (Midwife 15)*

However, not all contact with hospital care has been disrespectful, as one participant discusses:

> *"'Well, [name midwife], you have so much experience, when YOU send someone to us it must really be necessary.' […] If you come they know: yes, it is necessary, you have already tried everything, so we are not going to try that again. And yes, to me that is a basis of equality." (Midwife 20)*

Several of the participants report explicitly that they attach much value to being transparent about what they are doing. This means, that when they have a client who wants to go outside guidelines and have a home birth in a high risk pregnancy, they attempt to persuade her to go for at least one consultation in the local hospital. That way, the client is already known there, in case of the need for an urgent referral, and less eyebrows will be raised when she shows up during labor. The holistic midwives will usually accompany their clients during such a consultation:

> *"Because I don't want to be secretive. I explain that to people, too: I won't do that. We are going to the hospital together and we will have a conversation there. You can explain why you want this. Just so they know, and I also want there to be a record of it, so that we are welcome in case of a complication." (Midwife 5)*

In spite of this transparency, many participants report fear of legal repercussions. They are frequently threatened by regular caregivers with reports to the Health Inspection. Since the 2014 decision by the court cited previously there have been no more convictions, however, several cases have been investigated:

> *"And that obstetrician has threatened that, actually. […] Like: 'I think we are going to have to report this. It is not right, and when you are facing the Disciplinary Board, then…' Like that." (Midwife 5)*

> *"And she [community midwife] threatened me that if I would not stick to the protocol that she would go public and publish it in the newspapers and that sort of thing." (Midwife 6)*

This has led one of the participants to avoid the openness avowed by the majority, and try to keep her work outside guidelines out of the public eye. However, most participants are not fazed by threats:

> *"I don't want to be so afraid of such an institution [Health Inspection] that I can't serve my women anymore, actually. That is what it comes down to."* (*Midwife 19)*

To share the burden of working the way they do, most of the participants are part of a network of likeminded caregivers. They have a private facebook page they use to communicate, discuss cases and support each other in case of trouble or a bad outcome, and they are often back-up to each other. Some also have connections in a (local) hospital, where they know they can go if they need help or want to discuss a case:

> *"This was a very kind doctor. I dropped her name in our little club, like: 'If you want something different, some time, you can try it there.' […] I was very content with that." (Midwife 13)*

Working on a case-load basis can be very demanding. Due to the fact that there are very few midwives who will accept births outside guidelines, participants sometimes have to travel significant distances to reach their laboring clients. Some mention a limit of 45 minutes to an hour, some say that if the need is

urgent there is no limit to how far they will travel. In addition, few clients means little income, although a number of participants supplement this by asking extra fees from clients. As case-load midwives, they are always on call:

> *"I almost never have a holiday, that is the downside. So I am really almost always available. […] Yes, I always have my telephone… Always, yes, yes. I don't know if the others have told you this, but yes, we really have a kind of phobia with that telephone. That telephone is always there, so you always know where your telephone is. That is the downside of working like this." (Midwife 9)*

When working with a client who wishes to deviate from guidelines, holistic midwives spend extra time on preparation: going over their clients wishes, checking their own suitability and skills, and making extensive case notes. For instance, if their client will not allow them to monitor the baby and refer to the hospital if necessary, they try to ascertain what it is their client does want from them:

> *"You know, if people are not willing to be referred, then I wonder what they want with me? What am I doing there?" (Midwife 19)*

In addition, the participants spend a lot of time meticulously documenting all conversations with their clients, both before and during the birth, since that documentation will be their only line of defense in case of a possible case brought by the Health Inspection:

> *"So I wrote down: 'I have offered to listen to the heartbeat. She refused.' (Midwife 13)*

Two of the participants had experienced a bad outcome. This has not changed their practice, however, it has been a significant burden on their minds:

> *"And then it is a rollercoaster you end up in. […] The Health Inspection, and…. opinions of others and support of others. Sleepless nights…"* (*Midwife 3)*

Although all participants are convinced that their clients do not take decisions regarding their baby's safety lightly, some still feel the burden of responsibility when clients appear to take decisions that pose increased risk to the baby:

> *"[..] I find that, if a mother chooses that, she knows very well what she is choosing, but a baby doesn't know what it chooses. […] It doesn't choose. So it doesn't choose to be born breech at home, or it doesn't choose to be a twin home birth. The parents*

choose that and therefore I find that more difficult than when someone with a previous post partum hemorrhage wants to stay home, or with heparin, if they have a clotting disorder. That to me is self determination over your own body." (Midwife 17)

Future directions

After discussing their motivations for working the way they do, and explaining the difficulties they sometimes face, the participants were asked what they would like to change about maternity care, if they could. Several participants suggested that hospitals and community midwives should start by implementing true informed consent and shared decision making in every consultation:

"If there was one thing [I could change], then it would actually be: try your best then, to get to know someone. And what motivates someone, and then often it won't even be so unreasonable." (Midwife 7)

Participants also called for more flexibility and continuity of care in the regular system. Several mentioned as example an integrated care protocol of one of the Dutch university hospitals, in which primary care midwives can stay with and assist their clients during a VBAC, as long as hospital protocol (continuous monitoring) is followed. Several of the participants came up with creative solutions to improve maternity care, for instance: obstetricians making house calls, or starting a chain of dedicated breech clinics:

"I would really like a sort of breech center. Somewhere in the country, where there is a bath, and a midwife, and a woman-friendly obstetrician, who says: 'Come on, we'll let this woman give birth the way she wants to give birth.' To actually study that, and publish results. (Midwife 1)

Finally, most of the participants reflected that they did not want to completely separate themselves from regular maternity care. They wanted to stay in the system and teach others, and work from the inside to improve the situation for their women:

"Some things have been set in motion, I think. I really do think those [integrated care] pathways have come about because we showed up quite a lot with people with these sorts of wishes, that we now have those pathways for. So there is a point to it after all. And I am going to keep doing it in the interest of caring for my women." (Midwife 13)

Core theme: addressing a need

The one pervasive theme that emanates from all interviews is that all participants feel the responsibility to be there for women who have, in the women's own view, nowhere else to go. These midwives believe that there is a need for their services, since regular maternity care in the Netherlands is letting women down by not leaving enough room for physiological birth and not providing enough time, continuity, flexibility and respect for autonomy:

> *"And then, for me, it became an activist kind of thing, like: this is very important, that we take a stand for this […], that women are entitled to their bodily integrity at all times, and can refuse care, but in the mean time should not be denied care." (Midwife 12)*

The participants in this study claim that they are meeting women's needs by establishing a relationship built on trust, empowerment and mutual respect, by taking the time to get to know their clients, in order to serve them better, and by being available as a last resort for these women.

> *"And so in some way I was the final destination, because after me there was nobody else who could say: oh well, go to the next midwife, she will do it, she will help you. […] Yes, someone had to be with that woman, somebody had to do it, you know." (Midwife 6)*

These midwives truly address the need for client centered care, and also hope, by suggesting future directions, that regular maternity care will follow their lead. This sometimes comes at considerable cost to the midwife herself, both in her relationships with other care providers and in her personal life.

> *"And that is why I feel it is a bit unfair, if an obstetrician says: 'The way you do it, you create this demand.' I am only trying to facilitate what is already there." (Midwife 13)*

Discussion

Holistic midwifery is a relatively new phenomenon in the Netherlands. For this qualitative study into the motivations and practices of Dutch holistic midwives, 24 midwives were interviewed. Four main themes were found, which all led back to one core theme: addressing a need. Despite the fact that the Netherlands has an integrated home birth system and relatively low intervention rates

compared to other developed countries, these midwives feel very strongly that there is a need among Dutch pregnant women that is not being met in the current maternity care system. We will now discuss this need and look at possible solutions.

Identifying the need: what is lacking in current maternity care?

A physiological approach

According to the participants in this study, the women that seek their services are dissatisfied with current maternity care because their needs are not being met there. Participants feel that these women need less risk talk, more flexibility, more continuity of care, and more room for a physiological approach to childbirth.

Historically, childbirth has always been perceived as a natural physiological process, which will usually proceed without incident with a midwife in attendance, unless complications arise. Doctors in hospitals took care of pathological childbirth, where the normal physiological process had gone awry. In recent decades, with more and more births occurring in hospitals, framing of childbirth has moved from a physiological perspective (everything is normal until it is not) to a medical model (childbirth is risky and only normal in retrospect). The lack of room in regular maternity care for a physiological approach to childbirth is a well recognized phenomenon in developed countries in recent years. For instance in the UK, where Scamel and Alaszewski point out "In midwifery conversation, normality has no language of its own and has to be defined against the dominant discourse of high risk" [17 p.216]. This lack of a physiological approach has also been reported in Ireland, where Healy [18] describes how the obstetricians' views on risk have increasingly prevailed over those of the midwife, whereby even low risk women are routinely required to labor on a continuous fetal monitor.

A different risk discourse

Participants in the current study felt that a change in risk perception and risk communication in the regular system was a strong contributing factor in women's decision to approach them as holistic midwives, or even give birth unassisted. According to Plested and Kirkham [19], this emphasis on 'risk talk' has also become common in the UK, where the authors describe women turning away from maternity care providers who think too much in 'risks' and don't convey enough trust in normal birth, thereby causing some women to lose trust in their care providers. Jenkinson et al. [20] in Australia report how clinicians' negative experiences (in obstetrics) could lead them to take a more risk-averse stance, where even having a birth plan does not protect women against ongoing discussions of risk and against pressure to consent to recommended care.

Flexibility

Another need described by participants as lacking in regular maternity care was flexibility in use of protocols. Most participants stated that clients frequently approached them because they had encountered a lack of flexibility in regular care. This is substantiated by a recent study among Dutch women who had a home birth in a high risk pregnancy or an unassisted childbirth in the Netherlands [9]. Many women in that study did not necessarily want a home birth, but found no room in the hospital to deviate even a little bit from standard protocol. It is common for care providers to be afraid of legal ramifications if there is a bad outcome while protocol was not followed completely, even though, by law, health care professionals are responsible only for adverse outcomes caused by their own negligent actions [21], not by decisions made by autonomous patients. Another reason for inflexibility could be that care providers fear bad outcomes in light of the ongoing discussion about perinatal mortality statistics [22]. In addition, according to Kotaska [23], care providers may lack flexibility, because they have the erroneous perception that deviating from guidelines always carries a high risk, when often this is not the case. In fact, deviating is allowed and sometimes even necessary, provided the reasons for deviating are well documented.

Continuity

Other needs described by participants that were not being met in the regular system were time, attention, continuity, autonomy and shared decision making. According to the participants, these were important factors which led women to seek out a holistic midwife. Lack of continuity can lead women to doubt whether or not they can trust that their birth plan will be respected, since, as Quinn puts it: "Lots of discussion beforehand and carefully negotiated treaties don't turn out to be altogether reliable" [24 p.13]. Women then turn to holistic midwives, where they know they will find continuity of care and can trust that their birth plan will be respected [25]. A recent Dutch study emphasized the importance of continuity, when they found that transfer of care and lack of continuity led to problematic communication and dissatisfaction on the part of the women [26]. Another study showed that, in the Netherlands, continuity of care as experienced by women is significantly higher in a midwife-led care model [27]. As Davison et al. also found in Australia: in order to be able to trust their providers, women need to be able to build a personal relationship with them [28].

Too many traumatic experiences

Participants in the current study often mentioned women being traumatized in regular maternity care. This is a recurring theme in literature on women choosing a home birth in a high risk pregnancy or an unassisted childbirth

[8,9,24,29]. In the UK, Symon et al examined perinatal mortality cases in holistic midwifery, and also found that in some cases, the women who had turned to a holistic midwife had been traumatized in the regular system [30].

In summary, the need for a more physiological approach, for less risk talk, and for more time, flexibility and autonomy leads some women to holistic midwives and a home birth in a high risk pregnancy.

Why now? A historical perspective

The appearance of holistic midwives in Dutch maternity care is a relatively new development, which needs to be examined more closely. It seems plausible that the need for holistic midwives in the Netherlands has arisen through a combination of gradual changes in society and maternity care, combined with developments in patient agency, such as the growing emphasis on shared decision making and increasing personal responsibility for one's health issues. As stated in the beginning of the results section, the first Dutch holistic midwife started her current way of practicing around the year 2000. It took several years for a second holistic midwife to join her, but by the beginning of the next decade there were more than a dozen, and current (2018) estimates range between 20 and 30 holistic midwives active in the Netherlands. In contrast , in 2016 there were 2315 practicing community midwifery members of the Royal Dutch Organisation of Midwives [31]. The group of holistic midwives therefore represents about one percent of all working community midwives in the Netherlands.

From home to hospital

For centuries, midwives were present for most births, which usually took place at home. In most developed countries, this changed gradually in the first half of the last century, with midwives losing their primacy, even in physiological births. With the increase of medical knowledge and treatment options for the prevention of adverse maternal and perinatal outcome, maternity care moved into the domain of hospitals, where doctors and nurses took control over what is in essence a natural process [32]. Midwives were still involved, but no longer in the capacity of lead caregiver [18,33]. In the Netherlands, this move towards hospital care did not occur, at least not to the extent that it did elsewhere. Around 87% of women still start their pregnancy in a community midwifery practice, and about one in three women still deliver in primary care with their community midwife, either at home or in a hospital or birth center [3].

However, over recent decades, the percentage of Dutch women being referred for secondary care at some point during pregnancy, birth or postpartum, has more than doubled, from 24.7% in 1964 to 58.3% in 2015 [3,34]. This is due to

both an increase in (perception of) pathology, and the demands for hospital care and/or pain relief by the women themselves [35] as well as a presumed increase of protocollized care. As a result, the majority of women in the Netherlands currently encounter both community midwives and hospital staff (obstetricians, trainees and clinical midwives) during pregnancy and/or childbirth. As Offerhaus states: "The persisting rise in referrals challenges the sustainability of the current strict role division between primary and secondary maternity care in the Netherlands" [36 p. 192].

More providers per woman

Where in 1980 in the Netherlands, more than two-thirds of community midwives worked as solo practitioners and 8.8% in a group of three or more, by the year 2015 this had become the opposite, with only 5% of midwives working solo, and 80% in a group of three or more [1]. In addition, group practices have been growing in size, with groups of six to eight midwives being common in recent years. The same phenomenon has occurred in hospitals, where, due to several factors such as feminization of the profession, increase in part-time work and mergers between different hospitals, women are now likely to see obstetrical groups of not three to five obstetricians, but frequently between ten and twenty [1]. In 1980, there were 7.5 maternity care providers per 1000 pregnant Dutch women, whereas in the year 2015, this had grown to 24.3 [1,31,37]. Therefore, the number of representatives of both professions that women encounter has more than tripled in the past four decades. Although continuity of carer is not the same as continuity of care [38], and not all women find continuity of carer a priority [39], for some women it may be difficult to negotiate a birth plan with a different provider at each visit [33]. In summary, the average Dutch pregnant woman is likely to see many more different caregivers during her pregnancy and peripartum than several decades ago.

The arrival of evidence-based medicine

These developments have coincided with the advent of evidence-based medicine. Where in earlier times practitioners based their decisions on their own training and personal experiences, with the arrival of protocols and guidelines, there is less room for negotiation between client and caregiver, since the recommended care is often clearly outlined in the protocol. In addition, practitioners feel more at risk of facing a lawsuit or disciplinary charges than they did circa 1980, making deviating from protocol feel hazardous. Finally, in 2009 perinatal audit was introduced in the Netherlands, increasing the focus of maternity care providers on substandard care and heightening awareness of the possibility of having to explain one's actions at a later time.

An increase in patient agency

At the same time, society has changed. People have become more self-reliant and medical practitioners don't occupy their previous position of authority any more [40]. Developments in patient emancipation have led to a great emphasis on shared decision making, patient autonomy and self-determination. Shared decision making has quickly been adopted by most professional organizations for obstetricians and midwives, who now avow "patient-centered care". In recent years, patient-centered care has become a cornerstone of every new guideline or protocol. The Royal Dutch Organisation of Midwives' professional code states that all care should be tailored to the individual woman's needs and wishes [41]. In 2016, all stakeholders in Dutch maternity care published a report and recommendations for shaping maternity care in the years to come [42]. This report is filled with statements about putting the client first. However, as Kotaska states, "guideline-centered care" is what may currently often be practiced [23]. In 2015, the Dutch Organization for Obstetrics and Gynecology issued a joint guideline with the Royal Dutch Organization of Midwives, detailing a management plan for caregivers confronted with pregnant women who wish to deviate from guidelines and are willing to accept less care than recommended [43]. Around the same time, the American Congress of Obstetricians and Gynecologists released a guideline entitled "Refusal of medically recommended treatment during pregnancy" [44]. According to both guidelines, in case of disagreement between provider and patient, a woman's autonomy should always prevail.

In summary, in current society, women are encouraged to make a birth plan, take responsibility for their own health and exert their autonomy, while at the same time their choices are being restricted by their providers' strict adherence to an increasing number of protocols and guidelines. Women are confronted with a large number of different caregivers with whom they have no opportunity to build a trusting relationship, which, according to the participants in this study, is the foundation of and a prerequisite for client centered care. Most women seem to accept the situation, but a small group of often highly educated critical maternity care consumers decides to take control of the management of their own pregnancies and look for a different approach. These developments could well be a decisive factor in the experienced increase in need for holistic maternity care by the participants in the current study.

Holistic midwifery in the Netherlands: a heavy burden?

A last resort

Addressing this need takes a heavy toll on holistic midwives. There are currently less than thirty midwives in the country working in this setting. All participants in the current study expressed great love for their job and a motivation to go

forward. They believed that their work was vital in order to be able to offer women the care they needed and couldn't find in the regular maternity care system. Just as reported by Symon et al [30], they felt that in many cases, if it had not been for them, women would have felt no other option than to give birth at home unassisted.

Pressure from outside

However, participants also voiced several drawbacks to being a holistic midwife in the current system of maternity care. Most importantly, participants felt a great deal of pressure by regular caregivers to stop attending high risk home births. Among other things, they were often accused of creating the demand they were facilitating, since several holistic midwives refer to care options outside protocol on their professional websites or in blogposts [45-48]. Some were also threatened with reports to the Health Inspection. Even though the initial three midwives in the court case referenced earlier had been cleared of all wrongdoing, many of the participants still felt anxious. They felt the pressure of constantly being judged by regular care providers, whose hostility, distrust and animosity weighed heavily on their minds. This is in accordance with the findings of Jefford and Jomeen [49], who report that independent midwives spoke of feeling 'out on a limb' and of 'being blamed' for women's refusals, and of Symon et al. [30], who found that hospitals did not respect holistic midwives' expertise. Another burden mentioned by those participants who worked case-load was the constant availability. They always had to be ready to leave at a moment's notice, which meant that for those who had children, child care always had to be available too.

A dynamic field

Since participating in this study, nine of the 24 participants have changed their practice and are no longer working in a holistic setting. When asked about the reason for giving up their practice, the answer most frequently given was the pressure exerted by regular care providers and the threat of legal action being taken against them. Another often mentioned reason was the burden of constant availability. Other reasons were lack of support by their professional organization, and impossibility of meeting the insurance companies' criteria for reimbursement. None of the midwives who had quit her practice had done so over a bad outcome. On the other hand, five "new" midwives have started holistic case-load practices in the last two years, filling the gaps left by those who quit.

Strengths and limitations

Strengths

There are several strengths to this study. First, all authors have a background in maternity care and are very familiar with the Dutch system. This familiarity is reflected in the topic list. Second, for a qualitative study, it is extensive, with 24 midwives, encompassing nearly all known holistic midwives in The Netherlands. Participants came from all parts of the country, all age groups and differing levels of work experience. Third, it is the first study examining the phenomenon of holistic midwifery in the Netherlands, a country known for its high percentage of home births, with community midwifery being an integral part of regular maternity care. Fourth, it is part of the larger WONDER-study project, from which two literature studies, two qualitative studies and a survey have already been published. This allowed the interviewers to triangulate the themes from this study with those found in the previous interview study, as well as those known from the literature, which heightened the validity of the results of the current study.

Limitations

There are also some limitations to the current study. First, the fact that all authors are or have been part of the regular maternity care system may have motivated some participants to downplay their own involvement in their clients' choices. It is possible that some midwives not only provided care as a last resort, but may have actually encouraged their clients to have a home birth in a high risk pregnancy. Although this question was asked, it was denied by the participants, but conflicting information on this subject can be easily found on the (Dutch) internet [45-48]. Most of the themes mentioned by the participants correspond very well with those found by the same authors in their study on women's motivations to give birth outside guidelines [9]. Second, one could suggest that the findings of this study cannot be extrapolated to other countries, since the Netherlands has a unique system of maternity care in which home birth in case of low risk pregnancy is an integral part of regular maternity care. On the other hand, the themes found in this study are not very different from those found in studies examining holistic or "independent" midwifery elsewhere. Finally, the sampling method could be seen as a limitation. However, according to many of the participants, the number of midwives interviewed closely approximates the total number of holistic midwives active in the Netherlands at that time, so it seems unlikely that many major themes were missed.

Addressing the need: implications for practice

Preventing negative choices

It seems imperative for the current maternity care system to address the root causes of the need that drives women to holistic midwives and home births in high risk pregnancies. In such cases, holistic midwives are willing to deliver what could be considered "second best care", because for some women, they are the last resort before women feel they have no other option than to deliver unassisted. This situation is suboptimal for two reasons. First, many women did not initially choose a home birth with a holistic midwife, rather they felt driven to them. Often following an initial traumatic experience, women decide to take a more active role in the management plan for their next pregnancy and delivery, but encounter inflexible professionals, leading them to make a negative choice against the hospital, and for a home birth in a high risk pregnancy [9,50]. Second, there is good reason for medical professionals to recommend a hospital birth in certain high risk situations like twins or breech births. As Bastian et al. found in Australia, mortality rates for home birth were 1:14 for breeches and 1:7 for twins. However, they lay responsibility for these squarely at the door of maternity care providers, by stating that: "Overintervention and lack of choice for women with high risk pregnancies […] could well encourage some to choose home rather than hospital birth" [51 p.387].

True client-centered care

More attention for preventing traumatic childbirth experiences seems imperative in order to prevent a situation in which women have lost all confidence in regular maternity care. In order to meet women's needs, true client centered maternity care needs to become the norm. This means that the protocol or guideline is the starting point of the conversation, instead of the bottom line. This does not mean that clients are allowed to dictate whatever treatment they feel is best for them, rather, that client and provider explore the possible options together, with more emphasis on client preference and personal situation and less strict adherence to protocols.

Midwifery-led continuity of care

Another need that holistic midwives feel has to be addressed by regular maternity care is women's need for more time and continuity of carer. For some women, these are prerequisites for developing a trusting relationship. And as de Vries states, "If fear is not balanced with trust, women are driven to make unwise choices" [52 p.10]. However, as Thompson [53] found, if trust is there, women will often stay in the system. In addition, a model where care is coordinated by (a team of) midwives, in close partnership with obstetricians when indicated in

case of a high risk pregnancy, does not only lead to increased satisfaction on the part of the client, it also yields better obstetrical outcomes such as more spontaneous birth, less pain medication and less preterm birth [54].

However, regardless of all points raised above, it is likely that some women will always remain who will seek out the services of holistic midwives, since, as Shorten and Shorten state: "The question is whether some women who employ independent midwives will ever be able to find what they need within mainstream services" [55 p.2210].

Conclusion

This qualitative study analyzed the motivations and way of working of holistic midwives, a relatively small and new group of maternity care providers in the Netherlands, a country known for its physiological approach to childbirth and its integrated midwifery care. Four major themes were found: 1) The regular system is failing women, 2) The relationship as basis for empowerment, 3) Delivering client- centered care in the current system is demanding, and 4) Future directions. These themes all came together in one overarching theme which was "Addressing a need".

Holistic midwives appear to deliver an important service. They provide continuity of care and succeed in establishing a relationship with their clients built on trust and mutual respect, truly putting their clients' needs first. The type of care they deliver is actually that which both Dutch professional organizations encourage their respective members to provide. Holistic midwives may be the last resort before women choose to deliver unattended by any medical professional. In order to reduce women's negative choices which may place them and their unborn children at increased risk of a bad outcome, regular maternity care providers should focus on preventing traumatic childbirth experiences, while at the same time learning how to deliver second best care (in the eyes of the provider), so that no women will feel that regular care is no longer an option for them. Some women will always prefer the care of holistic midwives, but currently, many of those who do, feel that they have no other choice.

References

1) Nivel. Data from the registry of midwives. 2016. Retrieved from https://www.nivel.nl/sites/default/files/cijfers-uit-de-registratie-van-verloskundigen-peiling-jan-2016.pdf (accessed 27-03-2018).
2) Forster DA, McLachlan HL, Davey MA, Biro MA, Farrell T, Gold L, et al. Continuity of care by a primary midwife (caseload midwifery) increases women's satisfaction with antenatal, intrapartum and postpartum care: results from the COSMOS randomised controlled trial. BMC Pregnancy Childbirth. 2016 Feb 3;16:28.
3) Perined. Perinatal Care in the Netherlands. 2016. Retrieved from https://assets.perined.nl/docs/7935f9c6-eaac-4f59-a150-307ae04efa27.pdf (accessed 27-03-2018).
4) Mitchell ED. Holistic midwifery--the reality. RCM Midwives J. 2002 Dec;Suppl:4.
5) Boenigk M. Interactive engagement and holistic midwifery. Pract Midwife. 2007 Apr;10(4):18-9.
6) State Newspaper. Verdict of Central Disciplinary Board. 2014. Retrieved from https://zoek.officielebekendmakingen.nl/stcrt-2014-18656.html (accessed 27-03-2018).
7) Hollander M, van Dillen J, Lagro-Janssen T, van Leeuwen E, Duijst W, Vandenbussche F. Women refusing standard obstetric care: maternal-fetal conflict or doctor-patient conflict? J Preg Child Health 2016; 3:2.
8) Holten L, de Miranda E. Women's motivations for having unassisted childbirth or high-risk home birth: An exploration of the literature on 'birthing outside the system'. Midwifery 2016;38:55–62.
9) Hollander M, de Miranda E, van Dillen J, de Graaf I, Vandenbussche F, Holten L. Women's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis. *BMC Pregnancy and Childbirth 2017; 17*:423.
10) Hollander M, Holten L, Leusink A, van Dillen J, de Miranda E. Less or more? Maternal requests that go against medical advice. Women and Birth 2018 Feb 10. pii: S1871-5192(17)30703-5.
11) Chervenak et al. Planned home birth: the professional responsibility response. Am J Obstet Gynecol. 2013 Jan;208(1):31-8.
12) Danerek M, Maršál K, Cuttini M, Lingman G, Nilstun T, Dykes A-K. Attitudes of Midwives in 774 Sweden Toward a Woman's Refusal of an Emergency Cesarean Section or a Cesarean Section on 775 Request. Birth 2011; 38(1): 71-9.
13) Jenkinson B, Kruske S, Kildea S. The experiences of women, midwives and obstetricians when women decline recommended maternity care: A feminist thematic analysis. Midwifery. 2017 Sep;52:1-10.
14) MacDorman MF, Declercq E, Mathews TJ. Recent Trends in Out-of-Hospital Births in the United States. J Midwifery Womens Health. 2013 Sep-Oct;58(5):494-501.
15) Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19(6):349–357.
16) Charmaz K. Constructing grounded theory. A practical guide through qualitative analysis. 2nd ed. London: Sage publications; 2007.
17) Scamell M, Alaszewski A. Fateful moments and the categorisation of risk: Midwifery practice and the ever-narrowing window of normality during childbirth. Health, Risk &Society 2012;14(2): 207-221.
18) Healy S, Humphreys E, Kennedy C. A qualitative exploration of how midwives' and obstetricians' perception of risk affects care practices for low-risk women and normal birth. Women Birth. 2017 Oct;30(5):367-375.
19) Plested M, Kirkham M. Risk and fear in the lived experience of birth without a midwife. Midwifery. 2016 Jul;38:29-34.
20) Jenkinson B, Kruske S, Stapleton H, Beckmann M, Reynolds M, Kildea S. Women's, midwives' and obstetricians' experiences of a structured process to document refusal of recommended maternity care. Women Birth. 2016 Dec;29(6):531-541.
21) Kruske S, Young K, Jenkinson B, Catchlove A. Maternity care providers' perceptions of women's autonomy and the law. BMC Pregnancy Childbirth. 2013 Apr 4;13:84.

22) Euro Peristat. The European Perinatal Health Report 2010. 2010. Retrieved from http://www.europeristat.com/reports/european-perinatal-health-report-2010.html (accessed 28-03-2018).
23) Kotaska A. Guideline-centered care: a two-edged sword. Birth. 2011 Jun;38(2):97-8.
24) Feeley, C, Burns, E, Adams, E, Thomson, G. Why do some women choose to freebirth? A meta-thematic synthesis, part one. Evidence Based Midwifery 2015;13:4–9.
25) Harris G. Homebirth and independent midwifery. Aust Coll Midwives Inc J. 2000 Jul;13(2):10-6.
26) van Stenus CMV, Gotink M, Boere-Boonekamp MM, Sools A, Need A. Through the client's eyes: using narratives to explore experiences of care transfers during pregnancy, childbirth, and the neonatal period. BMC Pregnancy Childbirth. 2017 Jun 12;17(1):182.
27) Perdok H, Verhoeven CJ, van Dillen J, Schuitmaker TJ, Hoogendoorn K, Colli J, Schellevis FG, de Jonge A. Continuity of care is an important and distinct aspect of childbirth experience: findings of a survey evaluating experienced continuity of care, experienced quality of care and women's perception of labor. BMC Pregnancy Childbirth. 2018 Jan 8;18(1):13.
28) Davison C, Hauck YL, Bayes SJ, Kuliukas LJ, Wood J. The relationship is everything: Women's reasons for choosing a privately practising midwife in Western Australia. Midwifery. 2015 Aug;31(8):772-8.
29) Hollander MH, van Hastenberg E, van Dillen J, van Pampus MG, de Miranda E, Stramrood CAI. Preventing traumatic childbirth experiences: 2192 women's perceptions and views. Arch Womens Ment Health. 2017 Aug;20(4):515-523.
30) Symon A, Winter C, Donnan PT, Kirkham M. Examining autonomy's boundaries: a follow-up review of perinatal mortality cases in UK independent midwifery. Birth. 2010 Dec;37(4):280-7.
31) KNOV (Royal Dutch Organisation of Midwives), personal communication, February 2016.
32) Fahy K. An Australian history of the subordination of midwifery. Women Birth. 2007 Mar;20(1):25-9.
33) Sandall J. Choice, continuity and control: changing midwifery, towards a sociological perspective. Midwifery. 1995 Dec;11(4):201-9.
34) Amelink-Verburg MP, Buitendijk SE. Pregnancy and labour in the Dutch maternity care system: what is normal? The role division between midwives and obstetricians. J Midwifery Womens Health. 2010 May-Jun;55(3):216-25.
35) Christiaens W, Nieuwenhuijze MJ, de Vries R. Trends in the medicalisation of childbirth in Flanders and the Netherlands. Midwifery 2013 Jan;29(1):e1-8.
36) Offerhaus PM, Hukkelhoven CW, de Jonge A, van der Pal-de Bruin KM, Scheepers PL, Lagro-Janssen AL. Persisting rise in referrals during labor in primary midwife-led care in the Netherlands. Birth. 2013 Sep;40(3):192-201.
37) NVOG (Dutch Organisation of Obstetricians and Gynaecologists): personal communication of the secretary of the history section, 2016.
38) Green, J, Renfrew, M, Curtis, P. Continuity of carer: What matters to women? A review of the evidence. Midwifery 2000 Sep;16(3):186-96.
39) Freeman LM. Continuity of carer and partnership. A review of the literature. Women Birth. 2006 Jul;19(2):39-44.
40) McIntyre MJ, Francis K, Chapman Y. National review of maternity services 2008: women influencing change. BMC Pregnancy Childbirth. 2011 Jul 16;11:53.
41) KNOV. Professional Code for Midwives. 2009. Retrieved from https://www.knov.nl/serve/file/knov.nl/knov_downloads/1801/file/KNOV_Beroepscode_van_Verloskundigen_2009.pdf (accessed 27-3-2018).
42) College of Perinatal Care. Care Standard for Integral Maternity Care. 2016. Retrieved from: https://www.knov.nl/serve/file/knov.nl/knov_downloads/2564/file/Zorgstandaard_Integrale_Geboortezorg_1._28_juni_20161.pdf (accessed 27-03-2018).
43) NVOG and KNOV. Guideline "Maternity Care Outside Guidelines. 2015. Retrieved from http://nvog-documenten.nl/uploaded/docs/KNOV%20en%20NVOG%20Leidraad%20Verloskundige%20zorg%20buiten%20richtlijnen%20ek.pdf (accessed 27-03-2018).

44) ACOG. Committee Opinion "Refusal of Medically Recommended Treatment During Pregnancy". 2016. Retrieved from: https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Ethics/Refusal-of-Medically-Recommended-Treatment-During-Pregnancy (accessed 27-03-2018).
45) Korteweg AM. Freebirth Blogspot. 2013. Retrieved from http://vrijegeboorte.blogspot.nl/search/label/Bewuste%20vroedvrouwen (accessed 27-03-2018).
46) Huese M. Midwifery Practice. Retrieved from http://vpmh.nl (accessed 27-03-2018).
47) Korteweg AM. Freebirth Blogspot. 2011. Retrieved from http://vrijegeboorte.blogspot.nl/2011/03/vroede-vrouwen-in-nederland.html (accessed 27-03-2018).
48) Verschelling M. A Holistic Midwife: why? 2016. Retrieved from http://oermoedersvannu.nl/artikel/een-holistisch-verloskundige-waarom/ (accessed 27-03-2018).
49) Jefford E and Jomeen J. "Midwifery Abdication": A Finding From an Interpretive Study. Int J Childbirth Volume 5, Issue 3, 2015: 116-125.
50) Holten L, Hollander M, de Miranda E. When the hospital is no longer an option. Defining moments for women choosing home birth in high risk pregnancies in the Netherlands: a multiple case study. Qual Health Res. 2018 Oct;28(12):1883-1896.
51) Bastian H, Keirse MJ, Lancaster PA. Perinatal death associated with planned home birth in Australia: population based study. BMJ. 1998 Aug 8;317(7155):384-8.
52) De Vries RG. Midwives, obstetrics, fear, and trust: a four-part invention. J Perinat Educ. 2012 Winter;21(1):9-10.
53) Thompson A. Midwives' experiences of caring for women whose requests are not within clinical policies and guidelines. British Journal of Midwifery. Vol. 21 No. 8 pp 564–570.
54) Cochrane Database. Midwife-led continuity models of care compared with other models of care for women during pregnancy, birth and early parenting. 2016. Retrieved from: http://www.cochrane.org/CD004667/PREG_midwife-led-continuity-models-care-compared-other-models-care-women-during-pregnancy-birth-and-early (accessed 27-03-2018).
55) Shorten A, Shorten B. Independent midwifery care versus NHS care in the UK. BMJ. 2009 Jun 11;338:b2210.

5

‘She convinced me’- Partner involvement in choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis.

Submitted
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Abstract

Background

Home births in high risk pregnancies and unassisted childbirth seem to be increasing in the Netherlands. There is a lack of qualitative data on women's partners' involvement in these choices in the Dutch maternity care system, where integrated midwifery care and home birth are regular options in low risk pregnancies. The majority of available literature focuses on the women's motivations, while the partner's influence on these decisions is much less well understood. We aimed to examine partners' involvement in the decision to birth outside the system, in order to provide medical professionals with insight and recommendations regarding their interactions with these partners in the outpatient clinic.

Methods

An exploratory qualitative research design with a constructivist approach and a grounded theory method were used. In-depth interviews were performed with twenty-one partners on their involvement in the decision to go against medical advice in choosing a high risk childbirth setting. Open, axial and selective coding of the interview data was done in order to generate themes.

Results

Four main themes were found: 1) Talking it through, 2) A shared vision, 3) Defending our views, and 4) Doing it together. One overarching theme emerged that covered all other themes: 'She convinced me'. These data show that the idea to choose a high risk birth setting almost invariably originated with the women, who did most of the research online, filtered the information and convinced the partners of the merit of their plans. Once the partners were convinced, they took a very active and supportive role in defending the plan to the outside world, as well as in preparing for the birth.

Conclusions

Maternity care providers can use these findings in cases where there is a discrepancy between the wishes of the woman and the advice of the professional, so they can attempt to involve partners actively during consultations in pregnancy. That will ensure that partners also receive information on all options, risks and benefits of possible birth choices, and that they are truly in support of a final plan.

Background

Since approximately the 1960's, men have been increasingly involved in the process of labor and birth, and are, in most western high income countries, generally expected to be present in the labor room[1]. However, many men still feel somewhat disassociated from the process: the majority don't attend most antenatal appointments and feel that maternity care providers don't really include them when they counsel their pregnant partners[2-5]. Because of this, many expectant fathers experience a lack of information, which they feel is a barrier to their involvement in the process of decision making concerning childbirth[6-14].

To date, there are limited data on partner involvement in decisions concerning place of birth and choice of birth attendant, neither when these choices conformed to the local maternity care system, nor when they were against medical advice.

In most high income countries, hospital birth has become the norm, and home birth, even in low risk pregnancies, is considered by mainstream maternity care providers as against medical advice[15]. However, the Netherlands, and, to a lesser extent, New Zealand, Canada and the United Kingdom, have a system in place where low risk pregnant women may opt for a home birth with a (community) midwife. Women with a high risk pregnancy are advised to go to a hospital to give birth under supervision of a gynecologist.

In the Netherlands, Hendrix et al.[16] investigated whether fathers participated in decision-making concerning the choice for home birth versus hospital birth in low risk women, and found that 60% of fathers reported that they were involved in the decision. In a recent study from the UK[17], where home birth in a low risk pregnancy is considered an acceptable choice, 21 male partners of low risk pregnant women were interviewed regarding their choice for place of birth. All partners stated that their choice for hospital was an automatic one, and that they would have been very unhappy if their wives had suggested the idea of home birth. This finding is in accordance with an Irish study by Sweeney et al.[18], who interviewed eight male partners whose wives opted for a home birth. All partners initially resisted the idea, even though it was (although an uncommon choice) not against medical advice.

Several studies have been done in countries where all home births are against medical advice. Three Scandinavian studies[19-21] and a Spanish study[22] have similar findings as the studies quoted above: the idea for a home birth came from the women. The men had doubts at first, but were eventually in agreement with the women. However, no studies have been done as yet in countries with integrated home birth for low risk women concerning partner involvement in the decision to go against medical advice and have a home birth in a high risk pregnancy or an unassisted childbirth (UC).

In the Netherlands, 30% of all births are attended by community midwives, about half of which are home births[23]. Almost all of these are low risk births, however, a small group of women chooses to have a home birth in a high risk pregnancy, attended by a community midwife. In addition, another small group opts for a UC, which is their legal right. Both choices are explicitly against medical advice. In 2017, we published a qualitative study among 28 women who made such a choice, examining their motivations for doing so[24]. The themes that emerged from these interviews centered around dissatisfaction with the regular system of maternity care, trust in nature and their own capacity for giving birth, conflict with maternity care professionals and a search for alternative care. An overarching theme of "fear" (of unnecessary interventions, loss of autonomy, and of provider's fear of legal consequences) was found.

This current study set out to examine the involvement of Dutch partners in the decision-making process concerning a home birth in a high risk pregnancy or UC in a country in which home birth for low risk women is integrated in regular maternity care. To that end, we interviewed the majority of the partners of the women who were the subject of our previous study.

Methods

The COREQ criteria for reporting qualitative research[25] were used to ensure a complete and correct approach to data collection and analysis. Permission for this study was sought from ethical committees of both the University of Amsterdam and the Radboud University in Nijmegen, the Netherlands. Both committees considered this study as not requiring ethical permission.

Research team

The majority of interviews (18) were conducted by the first and last authors (MH and LH), while the remaining five were conducted by three midwifery students under the supervision of the last author (LH). All interviewers are women, and both MH and LH are experienced in conducting interviews for qualitative studies. All interviewers have a background in midwifery/obstetrics, and LH also has a background in anthropology. EdM participated in designing the study, JvD, IdG, AS, FV and EdM gave constructive criticism on earlier drafts of this article, and approved the final version.

None of the partners were known to the interviewers prior to the interviews. The partners were aware that the interviewers had a professional interest in birth outside guidelines, women's rights and the Dutch maternity care system.

Study design

This exploratory qualitative research used a constructivist approach and a grounded theory method[26]. This study is part of a larger project exploring out of the system birth, the WONDER-study[27], in which we also interviewed women who went against medical advice in their birth choices (home birth in a high risk pregnancy or UC), their partners and their midwives. All partners were contacted through the women. The interviews with the women were the subject of previously published research by this group[24]. All partners who were asked for an interview agreed to be interviewed. Interviews were conducted between the summer of 2014 and the winter of 2016, and two partners were interviewed twice. Interviews concerned births that took place between 2010 and 2015. The majority of interviews took place in the partners' home, with one exception, which took place in a public place. Most often the partner was interviewed alone, although in several cases, the woman was present in the room and occasionally joined in the conversation. Location of the interview and presence of the woman was by partner's choice. All partners gave consent for their quotes to be used in this article.

Interviews were semi-structured by use of a topic list (Figure 1) but were allowed to flow freely, lasting between 30 and 75 minutes. The topic list was based on themes from the literature on women's motivations[28-32], and topics were added as new (sub-)themes if mentioned in other interviews. A digital sound recorder was used and data were then transcribed verbatim by either a commercial company or volunteer medical students. All data were stored anonymously in a password protected university database.

Data analysis

All interviews were coded by the first author (MH). Data analysis was done using qualitative data analysis program MaxQDA (VERBI GmbH™). After 10 interviews, the last author (LH) coded an interview as a peer review to see if any codes were missing, and one code was added. Coding was started from the bottom up, with each interview adding and building on the coding tree (Figure 2). Codes were then grouped into themes and subthemes. Data saturation was reached after 18 interviews. Consensus on the final coding tree was reached through discussion between MH and LH after all coding was completed. All quotes were translated from Dutch into English by MH.

Figure 1 Topic List. List of topics used during the interviews

Where did you partner intend to give birth? Alone or with a midwife?
Did you two have conversations about this? Who brought it up first? What were your thoughts?
Which factors do you believe influenced the decision to go against medical advice?
Did you see an increase in risk? Did you discuss this together? Did you make emergency plans?
What do you think a partner's role should be during the birth? How did you prepare?
Did you speak to others about your decision? What did they say?
How did the birth go? How was it for you, looking back now? Would you make the same choice again?
What is a good birth? What do you think of the current maternity care system?
What should we change?

Results

Twenty-one male partners were interviewed involving 27 births, the majority of which were UC's (7), home Vaginal Births after Cesarean (VBAC)'s (6), home breech births (4) and twin home births (2). There were 25 live births and two intra partum deaths. The intra partum deaths involved one case of a quick and uncomplicated term breech birth, where the baby was born without vital signs, resuscitated and died several days later. The other case was a protracted and unmonitored term VBAC, where the baby died during labor, presumably due to asphyxia. There was no ruptured uterus. This was confirmed afterwards at cesarean section. The age of the partners ranged from 24 to 43 years, with almost half (43%) being older than 35. Most partners (86%) were employed, and two thirds (62%) were highly educated, of whom five (24%) had a university degree. Two partners were of Moroccan descent, all others were ethnic Dutch. For a minority of the partners (21%), the birth relevant for the interview was their wife/girlfriend's first birth, while for most partners (67%), it was their wife/girlfriend's second and/or third birth which was the subject of the interview. Almost half (43%) of the secondary care indications concerned a planned VBAC. Demographic data can be found in Table 1.

Home births are described as 'attempted' when the birth was not completed at home and transfer to the hospital was necessary, and, in one case, as 'intended', when an ante partum complication occurred, making it necessary for the couple to abandon their plans for a UC.

After grounded theory analysis of the 23 interviews, four main themes emerged: "Talking it through", "A shared vision", "Defending our views", and

"Doing it together". After careful consideration of the data, one overarching theme emerged, which was "She convinced me".

Figure 2 Code Tree

Talking it through
- Previous bad experience in regular care
  - Traumatic experience
    . Partner felt she had failed as a woman
    . Working on dealing with the trauma
  - Bad communication skills
  - No flexibility
  - No continuity
  - Conflict in regular care
  - No informed consent
  - No shared decision making
    . Threats, legal action
    . Paternalism
- Dissatisfaction with the regular system
  - Things go wrong in hospitals too
  - Regular carers are afraid
    . Risk talk, exaggerating risk
      +Lack of information
  - EBM is limited
    . Interventions cause pathology, create risk
    . Carers interrupt the process
    . You need to tailor care
    . Midwife/obstetrician left us little choice/recommended hospital
    . Creating more and more conditions to be met
    . Guidelines are not laws
  - Hospitals only focus on the medical side
- She has done all/most of the research
  - Social media
- Weighing the risks
  - Deciding moment
    . We would have been willing to go to hospital
  - Letting go of fear
  - Accepting a bad outcome, dealing with a bad outcome
- But it's my baby too
  - But I prefer hospital just in case
  - But healthy mother and child are the most important

A shared vision
- Process of becoming a family
  - Long term effects on the child

Figure 2 Continued

- Birth is a natural event
  - You need to do what feels right
  - You need to be able to relax for a good birth
  - Trust
  - UC empowers women
- Her body, her choice
  - As long as she feels good about it

Defending our views
- Opinions of family and friends
  - Not discussing it
  - Spreading the word, convincing others
  - They suggested it
  - Going against medical advice is scary/difficult
    . Leading to doubts
    . They are the experts
    . People can point fingers if it goes badly
  - Fear of birth, aversion to risk
    . Difficult to explain, no understanding
    . You should follow advice
  - Favourable
- Protecting and defending her against caregivers
  - Going to the hospital in her place

Doing it together
- Preparations for birth
  - Getting tests
  - Designated clinic, getting all the information
    . Not discussing your plans with the hospital
    . Making sure the hospital knows our plans
  - Thinking about plan B
    . Willing to be referred if things go wrong
  - Taking a course
  - Doing research, reading up
- Writing a birth plan
  - Wanting and not getting a water birth
    . Water birth/birthing position
- Finding a midwife who agrees
  - Search for a new midwife halfway through
  - Holistic midwives are misunderstood
    . Holistic midwives should be reimbursed/more integrated
  - Travel distances, too late
  - Role of the midwife
    . To be there just in case
    . We don't need her (UC)
  - Connection with the midwife
- Men should have a larger role during pregnancy and birth
  - Catering to her needs

Talking it through: not an easy choice

In all but one case (an attempted home VBAC), the idea to go against medical advice and choose a UC or a home birth in a high risk pregnancy was first suggested to the partners by their wives/girlfriends, whereas the partners themselves had no strong personal feelings or preferences about the birth setting. Deciding to go against medical advice in their birth choices was not a decision that was made overnight. All partners reported that this required a substantial amount of "talking things through" in order for them to agree to the proposed plan.

Most of the partners in this study stated that the idea originated in a negative experience in regular maternity care. In either a previous or the current pregnancy, partners and their wives/girlfriends had experienced bad communication skills, paternalism, and a lack of flexibility, continuity, informed consent and shared decision making from maternity care providers. In many cases, there had been a conflict between the couple and providers, and in some cases even threats of legal action being taken by care providers against the couple:

> *"So it was the same again: "Aren't you afraid your child will die, your wife will die?' Really putting pressure on us and then I got a bit angry like: This isn't health care, this is not thinking things through together with people, this is only making things hard for them." (partner 8, home VBAC)*

Partners reported that, because of these negative experiences, their wives/girlfriends decided to look for an alternative to regular care. They stated that the women suggested the idea of going against medical advice after doing extensive research, mostly on social media, which was then presented to the partners:

> *"[She] really took all this in like a sponge, and spent night after night searching on Facebook groups about this subject, and the book 'Free Birth', […] and sometimes she would show me things." (partner 1, previous PPH and MPV)*

> *"[Wife] spent a lot of time searching the internet for all kinds of articles. I didn't have the opportunity to spend that much time on it, so…at one point I just assumed she knew more than I did." (partner 12, attempted twin home birth)*

During the interviews, it became clear that several partners had not done much research for themselves, rather they had been given limited information on the risks that the proposed birth plan entailed, and they appeared to be not quite

aware of what risks they were taking. It appeared that the information at their disposal largely originated from their wives/girlfriends, in contrast to what they might have been told by medical professionals if they had been present for most or all consultations:

> *"I wonder if this was a high risk pregnancy. Is this always considered high risk? […] OK, I did not experience this as high risk. […] Didn't realize, either. I did think it was higher risk than a singleton pregnancy, but…didn't really consciously think about it." (partner 14, twin home birth)*

> *"What are the chances of an actual uterine rupture? They are no larger than that a firstborn comes out with a prolapsed umbilical cord. […] So we felt like: what is the big deal?" (partner 20, attempted home VBAC, intra partum fetal death)*

The information presented to them by the women convinced the partners that interventions could also cause pathology, and presence of care providers could interrupt the process of childbirth. They felt that hospital care was only focused on the biomedical model of childbirth, not taking into account that giving birth is a major life event. In addition, they stressed that evidence based medicine is limited, and not always applicable:

> *"Giving birth is a natural thing. Basically, apart from a few complications, every woman can give birth normally. When you are in the hospital, it is a much smaller step […] to have an intervention. If you are not in the hospital, you will have to do more yourself. […] One intervention often leads to the next, with the whole cascade we had last time." (partner 21, UC)*

The partners had the impression that maternity care providers were afraid of legal consequences in case of a bad outcome, which would cause them to exaggerate risks communicated to the couple:

> *"We mostly encountered people who were very afraid. Very afraid things would go wrong." (partner 10, home breech birth)*

Midwives and obstetricians were accused of creating more and more conditions to be met, leaving the couples little choice but to either agree to all proposed measures or move outside the system and choose a home birth in a high risk pregnancy, or an unassisted childbirth:

"And every time they made up another reason not to agree [to what we wanted]." (partner 18, home VBAC)

Most couples had extensive conversations about the subject of a home birth in a high risk pregnancy, or an unassisted childbirth, in which they weighed the risks together:

"I was often aware that it is actually just…actually a big risk…that you are at home. And you have to wait ten minutes for an ambulance….and you don't have ten minutes." (partner 10, home breech birth)

Agreeing to support their wives/girlfriends in a decision to choose a home birth in a high risk pregnancy or a UC was not an easy choice to make for some partners, and required them to let go of their fears and embrace trust in a good outcome:

"Well, that was a difficult process for me too. Actually, everything that you encounter, that I could encounter, that I am afraid of….is that real, is it justified or is there a solution to be found?" (partner 19, UC)

After much discussion and soul-searching, partners reported that they were convinced by the women's arguments and agreed to their suggestions, which meant that they would also accept a bad outcome, if it came to that:

"We talked through the implications together. What it could mean and what we would do with this [a bad outcome]. We clearly said to each other: we make this choice and we take responsibility for it ourselves." (partner 9, home breech birth)

"What does it mean that things could go wrong? Both with [wife] and with [baby]. And what does this do to me? And what do we need to go down this path together?" (partner 16, intended UC)

In summary, a (previous) negative experience in regular maternity care led the partner's pregnant wives/girlfriends to suggest going against medical advice in their birth choices. This necessitated much discussion, during which the partners were convinced by the women's arguments about negative aspects of maternity care and their research on social media into alternative birth options, and agreed to go down this path, support their wife/girlfriend and accept responsibility for this decision and the outcome together.

Table 1 Partner characteristics (N=21, involving 27 deliveries)

Partner characteristics	N
Age at relevant delivery (years)	
20-25	2
>25-30	1
>30-35	9
>35-40	4
>40-45	5
Employed	
Yes	18
No (still a student)	3
Highest education	
High School	5
Vocational training	3
College	8
University	5
Ethnic origin	
Moroccan	2
Dutch	19
Marital status at time of relevant delivery	
Married	18
Living together	3
Indication for secondary care	14
VBAC (1 also diabetes type I)	6
Breech (1 also post term)	4
Twins	2
Previous postpartum hemorrhage (>1000 ml) and manual placenta removal	1
High body mass index (> 35)	1
Unassisted childbirth (UC)	7
Perinatal death	2
Breech	1
VBAC	1
Wife/girlfriend's parity after relevant delivery	
1	4
2	8
3	6
4	2
5	0
6	1

A shared vision

During discussions, the partners became convinced by the women's arguments, came to share their views on the best birth option for them, and agreed to the plan for a home birth in a high risk pregnancy, or an unassisted childbirth. This became a shared vision, in which not only the physical process of giving birth, but also the process of becoming a family played an important role:

> *"I come from a family myself, where closeness is very important. That is a home situation. I want it to be like that for my children, I want to create that and contribute to it. I think that has only strengthened our choice for home." (partner 6, UC)*

Many partners believed that the way the birth went and how the baby came into the world would affect the dynamics of their family, their bond with the baby, and perhaps even the character of the child:

> *"And the problem with [name child] actually was that we gave away too much [control] to those doctors, that our son did not actually have a connection with us. Not until much later. And that caused him a lot of stress. He slept badly. At home, he almost never slept. Awake a lot, crying a lot, those sort of things." (partner 18, home VBAC)*

Partners stated that they felt that birth is a natural event, which has the best chance of proceeding without problems if left alone. They were convinced that in order to have a good birth, you need to do what feels right for you, and women have to be able to relax and have faith in themselves and those around them:

> *"When a woman gets into the right mood, when she withdraws almost like an animal in the bushes and does her thing and closes off and when there is quiet and she makes her own [endorphins] or whatever is necessary, then birth will just take its course." (partner 1, previous PPH and MPV)*

For some partners the ultimate form of trust is unassisted childbirth:

> *"We are convinced that many things will sort themselves out if you just let things take their course and don't disturb […], then usually it will go well." (partner 4, UC)*

Several men stated that they believed it was very important for the woman to feel good about the plans for the impending birth, since she was going to be the one who had to give birth:

> *"What I can say about it, is that how [she] sees it and how [she] feels it, that that comes first. If [she] says now: '[next time] I want a C section up front', then I would find that very difficult, but eventually I would support that." (partner 17, home breech perinatal death)*

> *"And then I felt like: if this is what you want, we'll do it. Then there is only one thing I can do, and that is get behind her decision and support her in it." (partner 13, home VBAC)*

Almost all partners reported that through conversation with their wives/girlfriends, they had become convinced by the women's arguments and had developed a shared vision on the nature of childbirth, in which an intimate, undisturbed home environment played a large role in the chance of a successful normal birth.

Defending our views

Having established a shared vision, most partners broached the subject of going against medical advice with their family and friends. The reactions they encountered ranged from supportive to outright hostile. The most frequent response they received was an aversion to risk taking in childbirth, which led family members and friends to counsel against the couple's plans and in favor of a birth within protocol. Even though they had become convinced of the merit of the intended birth plan, partners found it difficult to explain their reasoning in their own social circle, which sometimes left them feeling insecure about the impending birth:

> *"Their first reaction was very intense: 'We do not approve of this! Do you even know what you are doing? You are insane!' All sorts of phrases rained down on us. And yes, that made me insecure." (partner 15, attempted home breech birth)*

Some family members/friends considered midwives and obstetricians to be the experts and couples were warned that people could point fingers if things ended badly:

> *"I think for every lay person, you know, who did not grow up with this, who grew up with the idea of: it happens in the hospital, so there will be a need for professionals… I think that can quickly give rise to the idea that having an unassisted home birth, with nobody there, not even a midwife, that is scary, that is dangerous, etcetera. That is, I think, the first reaction you have." (partner 16, intended UC)*

Some partners did not discuss their plans with anyone at all, whereas others were actually inspired by other couples of their acquaintance who had gone down the same route. A few couples encountered favorable responses from their social circle, and even attempted to convince others to make the same birth plans, after their birth had gone well:

> *"And when you tell people how it went and [they] think: 'Oh, I might want that too, or not, and [they] think: ok.' Yes, it is quite the conversation starter, and I think that is fun and nice." (partner 19, UC)*

In addition to having to defend their plans in their own social circle, some partners also felt they had to defend the women against their care providers. In two cases, the partners even went to a hospital appointment alone, without the woman, to confront their obstetrician:

> *"The last week before the due date the doctor wanted another meeting. [Wife] felt like: 'I don't want to talk unless he has something [new] to offer.' […] She didn't want to go, so I said: I will go and talk to him. […] It was a pretty stressful meeting. I was glad [wife] wasn't there. She had gone through enough." (partner 8, home VBAC)*

In conclusion, after having established a shared vision, most partners took it upon themselves to defend the couple's plans in their own social circle, and some attempted to convince others, sometimes against negative responses. In addition, two partners even confronted a medical professional in order to defend their wife/girlfriend's wishes.

Doing it together

Having developed a shared vision and discussed their intentions for the birth in their own social circle, the couples started preparing together for the birth they had decided on. Most of the partners were very supportive. Some reported taking a preparatory class like hypnobirthing together with their wives/girlfriends, or going with the women to a designated clinic for couples who are considering birth choices against medical advice, in order to get all the information available. Several couples discussed their intentions with an obstetrician at their local hospital, so there would be a record of the situation and their intentions in case they needed help during the birth:

> *"We went to the hospital just so we had seen them and to say: 'Look, if things unexpectedly go differently, then we will come here, because we live five minutes away, so this is the hospital we will go to.'" (partner 17, home breech perinatal death)*

Another way to prepare for an unassisted childbirth was getting some selected tests, so the couple would not be surprised during the birth by, for example, twins:

> *"With the fifth [child] we eventually had an ultrasound done. But that was more because there was so much movement inside her abdomen that we thought: OK, it looks like there are too many limbs there." (partner 5, UC)*

Some couples made extensive and well thought out plans together for what to do in case they came across certain complications during the birth, whereas others decided doing so would only become a self-fulfilling prophecy:

> *"Yes, I asked those questions, like what if she suddenly starts bleeding, you would have to call the ambulance. […] Or what if there is meconium in the water. Or what if the cord is around the head. […] [During the birth] I listened to [wife] very carefully for signs that she might need help.[…] If she would start acting funny then there would be a problem, but she didn't." (partner 5, UC)*

> *"But actually we did the same thing as when you get into a car. You don't think like: oh, if I get into an accident I will do such and such. We basically always assumed things would go well." (partner 4, UC)*

Most of the partners report writing an extensive birth plan together, often concerning intentions for a water birth. In a few cases, the unavailability of the option for a water birth in regular care was part of the process that led to the decision to choose home birth:

> *"Well, the hospitals in this area didn't offer that [a water birth]. That was confirmed during the conversation [in the clinic]. If during that conversation it had turned out that 'Listen, that is possible here, with [midwife]', […] you could do it in the bath, and…That didn't happen, so […] we would have had to go elsewhere for that." (partner 17, home breech perinatal death)*

For some couples, the choice for having a home birth in a high risk pregnancy meant they had to find another midwife, since obstetricians do not attend home births, and their regular community midwives were unwilling to attend a high risk birth at home. Having to find a new provider, sometimes in the final stages of pregnancy, was a source of stress for the partners and their wives/girlfriends. The few midwives that were willing to attend such births were few and far between, meaning that travel distances could be further than couples would have liked:

"That was quite a search. [wife] has telephoned a lot of people, and… look, because we were quite far along in the pregnancy, the time you have left is quite short. That may limit your options […]." (partner 11, home VBAC)

When a midwife was found, it was also considered important by partners that there would be a 'click', a connection with the midwife in question and that the wishes of the couple would come first, not the guidelines:

"When I shook her hand and looked into her eyes, I thought: this is the one." (partner 1, previous PPH and MPV)

"Someone to just be there, and attuned to our needs. Instead of us having to accommodate her, so to speak." (partner 19, UC)

In cases of intended unassisted childbirth, partners reported that they chose this option because the couple did not see a great deal of use for a midwife, other than just to be there in case problems arose during the birth:

"To my mind, the best scenario would be if you could deliver unassisted with a midwife present who just sits on the corner of the sofa with a cup of tea, and does nothing unless she is asked." (partner 4, UC)

Finally, partners spoke of what they believed their own role during the birth should be. Several partners stated that they felt the role of the partner during both pregnancy and birth should be much larger than it currently is:

"I think there is a world to gain in how you can help your wife to get in the right mood, that she almost detaches a little from the world, feels safe, calm, and…that the process gets going and the birth goes smoothly. […] Because right now, you are a bit like an appendage, you know…[…] You have your role, but you are not the one who will be doing it." (partner 1, previous PPH and MPV)

The partners wanted to be involved and felt that they should be both constant companion and defender of the woman, and help her get through the birth from start to finish, doing it together:

"Listen, you [as a partner] have a role during the birth. You need to make sure your wife is heard […], and not overwhelmed by all the medical stuff." (partner 5, UC)

"I can be there for you […]. I really want to be involved, and stay involved. And not that some protocol says I can't be there or I can't see certain things. I want to see them." (partner 15, attempted home breech birth)

In summary, in addition to defending the couple's ideas to others, partners also took an active role in making detailed plans for the birth and finding a new midwife. They felt that they should also have a larger role during the birth itself, helping and supporting their wife in giving birth in the way that she wanted.

'She convinced me'

After careful consideration of all four major themes and their subthemes, a pattern can be discerned, at the core of which is the process of the women convincing the partners of their views (Figure 3).

As stated previously, one partner brought up the idea of a home VBAC. In addition, two partners first suggested the idea of a water birth to the women, which may have been a factor in these couples' ultimate decision to go against medical advice, since water births are not always available in hospitals, or not for every high risk pregnancy. In all other cases, the women first suggested the idea for a home birth in a high risk pregnancy or a UC to the partners, did most of the research, and discussed what they had found. These discussions were in-depth, during which much soul-searching on the side of the partners took place. Through these discussions, the partners became convinced not only of the merit of the women's plans, but also of their objections to regular care and of their views on birth in general. This led to a shared vision for the desired care, and caused the partners to defend the birth plan to other parties, as well as actively participate in (preparations for) the actual event. Preparing for and going through the process of these births was, for most partners, an intense experience, which strengthened the bond in their relationship, and made them come through this stronger as a couple:

"The fact that she provided information for all my questions, either scientific articles or just other stories, you know. I thought: ok, well, this has been researched so thoroughly by her, that I thought, I can support this. […] It sort of happened to me, you know. She started doing the research and I sort of got sucked into it." (partner 2, home VBAC)

"It was mostly my wife, I have to say. What she gave to me, I read, but she was the one who did all the research. […] There is so much information on the internet. You can't just trust everything. […] But when she dives into something, she does it right, you know? […] But at first I was very critical. When I first heard of it [UC] I

thought…I don't know about this. It can't hurt to have somebody there. But when we talked about it a lot, and [wife] had explained to me what the effect can be of just somebody being present….then I understood what she meant and how it works. And then I was convinced in the end that we can do without [a midwife]" (partner 4, UC)

Figure 3 Main themes diagram

A negative case

Even in both cases where there was a bad outcome (perinatal death), the partners stated that, although things ended badly, they were still convinced the choice that was made was the right one, and they would make the same choice again if necessary. They reasoned that, when a decision is made on the right grounds, it is always the right decision, no matter how things end. However, one partner (partner 12, attempted twin home birth) differed from all other partners in respect that, in hindsight, he had some serious misgivings about the choices that were made prior to and during his wife's birth. She persuaded him to go along with her plan for home birth by showing him research she found online, which left him not entirely convinced:

"At some point you think: fine, you do the research then. On the other hand, it did occur to me: aren't you using those articles that are the most convenient for you? […]

> *I didn't know that much about it, true. Then I would have to search for studies myself which would refute what [she] found. Then what would we actually be doing? That makes no sense at all." (partner 12, attempted twin home birth)*

His wife found a midwife on the other side of the country, which also struck him as strange:

> *"I didn't actually realize that [our choices] were that unusual until [wife] said: 'I found a midwife from [across the country].' I thought: wow, what? If you have to go that far afield, [twin home birth] must be a strange step to take. […] I did not actually talk to the midwife until the birth itself and…then I was not completely convinced and sure that this was the right decision." (partner 12, attempted twin home birth)*

At one point he was no longer fully on board with proceeding with a home birth, as he felt his family was threatened by social services being called in due to his wife's refusal to go to the hospital:

> *"Until that point it was [wife's] birth, […] but at that moment something changed, because suddenly this was about my family too. […] I had reached the point where I thought: just give in and go to the hospital already, because….you may have some wishes concerning your birth, but how much are you willing to risk to make that happen?" (partner 12, attempted twin home birth)*

Much later, the partner and his wife discussed the situation, but still did not agree:

> *From what I saw of her here, I did not have a lot of confidence in [the midwife], I must say. […] It does not make conversations at home any easier. I have been told: 'You are just like those doctors.' Yes. It has been a pretty difficult time." (partner 12, attempted twin home birth)*

Discussion

This qualitative study involved in depth interviews with 21 male partners of Dutch women who gave birth at home in a high risk pregnancy or had an unassisted childbirth, choices that are explicitly against medical advice. Four main themes ("Talking it through", "A shared vision", "Defending our views", and "Doing it together") and one overarching theme ("She convinced me") were found.

The women take the lead and filter information

In all but one case, partners reported that the decision to go against medical advice originated with the woman. Unlike in the study by Bedwell et al.[17], not all partners in this study automatically assumed that the birth would take place in a hospital, even in cases of a high risk pregnancy. In fact, most of them initially had no firm views about the impending birth and would not have raised the idea of going outside conventional care themselves. This is in line with other studies[18-20,22,33], where the pregnant woman initiated conversations about birth options that were against convention or medical recommendation. Often these plans originated in a previous traumatic experience in maternity care, where the women experienced a cascade of interventions and lack of shared decision making[18,20,24,28]. The couples had extensive discussions about the women's suggested plans for the birth, during which the partners became convinced by the women's arguments and research that a UC or a home birth in a high risk pregnancy was truly the best thing for them and their child(-ren). The overarching theme of 'fear' (of unnecessary intervention, loss of autonomy, provider's fear of bad outcome and legal ramifications) from our previous study on women's motivations[24] was not found to be an important factor in this current study. It appears that, in accordance with Ryding et al.[34], for the women, fear played a large role in decision making, whereas the men did not initially fear the regular system with its interventions, but mostly followed the women.

In contrast with other studies[4,18,19,21,35], where male partners did a substantial amount of research themselves, many partners in this study stated that the women extensively researched the risks and benefits of their preferred birth plan online and through social media, and used these findings to convince them. This was successful in all cases, since all partners were happy with the final decision, even though one, our negative case, changed his mind during the birth. In addition, in accordance with the findings by Longworth[11] and Dejoy[33], several partners felt that it was 'her body, therefore her choice', and that they were happy with whatever the woman decided to do and would support her no matter what.

These conversations between the couples resulted in the men being convinced by the women's arguments, deciding to support the women's plans for the birth and coming to share the women's views. This shared vision was evident through remarkable similarities in statements about the regular maternity care system between the partners in this study and their wives/girlfriends in our previous study[24]. The interviews read like the women were a 'filter', through which the men acquired and interpreted information. This finding presents the ethical dilemma of care providers informing partners. Dutch law states that health care providers have an obligation to provide clear

information regarding treatment, alternative treatments and preventative services to their patients, treatment and preventative services to their patients, as long as they are competent to decide on matters pertaining to their own medical condition[36]. In the case of maternity services, this contract is with the woman. The medical professional is not required or even allowed to contact the partner to verify his understanding of the risks and benefits of the several options, or his opinion on the management plan. However, the woman's partner is presumably just as invested in the wellbeing of the child the woman is carrying as she is, and will be equally responsible for making decisions for the child as it's mother, after it is born. If the woman filters the information the partner receives, the partner may not be in possession of unbiased information from all possible sources and may therefore be unable to fully decide for himself how to weigh the risks and benefits of the proposed plan. However, it is not known how many of these partners were present at consultations with maternity care providers. It is possible that they did have the opportunity to be counseled by medical personnel, but simply attached more value to the arguments presented by their wife/girlfriend. In addition, even if partners had been present for most or all medical consultations, there is still no guarantee that medical personnel would have provided adequate counseling. Nonetheless, it seems possible that, as in our negative case, some partners of women who choose a high risk birth setting against medical advice may, in hindsight, be unhappy with decisions that were made. This could lead not only to marital conflicts, but also to remonstrations and dissatisfaction with health care professionals, if the partner feels that he would have made a different choice if he had been provided with all the existing evidence-based medical information.

The partner as engaged protector

As stated in the introduction, several previous studies have shown that, contrary to the findings of this study, men are quite often not very involved in the process of pregnancy and childbirth[2-5]. Engaged partners have been shown to have a positive effect on their children and their wives/girlfriends: Jeffery et al.[2] found that increased levels of partner engagement in pregnancy and childbirth leads to better birth outcomes, and to a better bond between father and child. This is confirmed by Draper et al.[37], who state that engaged fathers are better fathers to their children. In addition, Xue et al.[14] in their study from Singapore, found that a higher level of engagement in fathers leads to lower incidences of post partum depression in mothers, and to a better relationship between spouses.

The partners in the current study had a high level of engagement with the process of pregnancy and childbirth. They adopted the women's views on maternity care and their ideas for a birth against medical advice, and participated

extensively in the process leading up to and including the day of the birth of their child. Similar to studies by Jouhki et al.[20] and Viissainen[28], partners took on an active role participating in preparing for the birth, writing a birth plan, and discussing possible scenarios for which solutions were agreed on, making the men in this study appear to be very much engaged in the birth of their child. Dejoy in her 2011 dissertation on the role of male partners in decision making around childbirth, found six main roles for partners in this process[33]: bystander, researcher, interpreter, leader/decider, limiter/boundary setter and protector. Only the role of protector seems to apply to the partners in this study. Once they were convinced by their wife/girlfriend of the intended plan for the birth, they defended these views to their social circle. In accordance with the findings of Fenwick[3], Sweeney[18], Jouhki[20] and Lindgren[21], they encountered mostly negative reactions from friends and family.

Two partners went even further in their role as protector of the woman, and went to the hospital in her place to confront a maternity care provider. This phenomenon can also be found in the studies by Locock[4] and Draper[37], who also describe the partner advocating for his wife/girlfriend against medical personnel. The fact that these partners felt that they needed to attend a hospital appointment with a medical professional in the woman's place, is indication of an irreversible breakdown in communication and cooperation between the professionals and the women involved. It illustrates how, in cases of substantially differing views between women and their caregivers, both parties can end up on opposing sides to such an extent that further cooperation becomes impossible. This situation then leads to a defining moment to go against medical advice, as illustrated in a multiple case study by Holten et al.[38] The burden is on the professionals to prevent the situation from escalating, by metaphorically and physically positioning themselves beside the patient, instead of on opposite sides.

Implications for practice

Although partners in this study were very involved in planning and preparing for the birth of their child, it appears that the idea for a birth against medical advice (a home birth in a high risk pregnancy or an unassisted childbirth) originated almost exclusively with the women. This study shows, that in cases of birth wishes against recommendations, the women were the main and frequently the suspected only source of information for the men, and convinced the men of their ideas and plans. Therefore, when maternity care professionals are confronted with a pregnant woman who is planning on going against advice in her birth choices, it would be helpful to realize that she will most likely not make this decision alone. As Osamor and Grady[39] state, "Since 'others' will

always be part of the exercise of one's agency in some form or other, interdependence should be recognized as the norm rather than independence (p.3)." It may thus be helpful to strive to discuss the options, risks and benefits of all possible scenarios in the presence of the partner. Doing so will remove the 'filter' the woman may put on all the information he receives, and help him in making up his own mind with all available data. This requires awareness of caregivers of their own risk perception and the willingness to provide bias free evidence based information. Counseling in this manner could prevent recriminations and dissatisfaction on the side of the partner after the event, since, as Osamor and Grady[39] suggest (p.5): "In certain contexts, a woman making decisions alone implies that […] she is in fact bearing the burden of full responsibility and potential blame for those decisions."

Finally, a situation in which the chasm between professionals and pregnant women becomes so wide that it becomes necessary for the partner to advocate for the woman is an undesirable situation. Health care professionals should never allow themselves to end up on opposite sides from their patient, even if there is a disagreement on the best management plan. Instead, they should position themselves beside the woman, both physically and metaphorically. They should practice shared decision making[40], explore all options with the couple, using actual percentages rather than odds ratios, and discussing numbers needed to treat and numbers needed to harm. The aim of counseling should not be to frighten the couple into submitting to recommended treatment, but to fully inform. Furthermore, professionals should be willing to make compromises and allow for second best care in order to prevent, from the professionals' point of view, undesirable choices as the ones described in the article.

Strengths and limitations

There are several strengths to this study. First, for a qualitative study, it is large, with 21 in-depth interviews with men with varying levels of education and different ages. Second, it is the first study on partner involvement in decisions regarding birth choices against medical advice in the Netherlands. This is important because it is likely that these occurrences are relatively rare here, since home birth for low risk women is integrated in the regular maternity care system, and therefore not against medical advice. Third, it is part of a larger project[27], for which the wives/girlfriends of the men were also interviewed. This has helped us to triangulate the results of both studies, and has heightened validity. Last, data saturation was reached on not only the main themes, but also the subthemes.

Naturally, there are also several limitations to this study. First, in approximately a third of cases the wife/girlfriend was present during the interview, which may

have caused partners to give certain desirable answers. Second, we did not interview any partners whose wife/girlfriend wanted to go against medical advice in her birth choices, but where the partner convinced the woman to stay within regular maternity care. This is an important point, since it is likely that there may be many more of those cases, but they are impossible to trace, and therefore, no comparison on partner involvement in decision making can be made. Third, there was no member check in the form of either returning transcripts to the participants or organizing a feedback focus group. This was deemed impossible and/or impractical due to logistic and time restraints. However, we did not rely on field notes alone, rather, all interviews were transcribed verbatim. Therefore, there is little doubt concerning the actual words used by the participants. Finally, the interviews were performed by researchers from the field, with extensive background in Dutch maternity care, and a professional interest in birth choices against medical advice. It is possible that this fact influenced the tone and content of the interviews. Perhaps some participants were more, or less, negative about Dutch maternity care than they would otherwise have been. On the other hand, their professional expertise allowed the researchers to formulate pertinent questions, which helped in constructing a relevant topic list and likely added depth to the interviews.

Conclusion

This qualitative interview study examines the involvement of partners in decision making concerning choices for a high risk birth setting against medical advice in the Netherlands. Four main themes were found: 1) Talking it through, 2) A shared vision, 3) Defending our views, and 4) Doing it together. From the data, one overarching theme emerged, and that was "She convinced me". This study shows that the idea for having a home birth in a high risk pregnancy or an unassisted childbirth almost always originates with the women, who seem to be the main source of information for the partners. This information appears to be 'filtered' by the women, and convinces the partners of the merit of the women's plans. They adopt and assimilate the women's views on childbirth. They support these views, which are now shared, by defending the plan for a birth against medical advice in their social circle, as well as in contacts with maternity care providers. Once convinced, the partners are very involved in planning and preparing for the birth. Maternity care providers can use these data to attempt to involve partners more during consultations in pregnancy, especially in cases where there is a discrepancy between the wishes of the woman and the advice of the professional. That will ensure that partners also receive information on all

options, risks and benefits of possible birth choices, and that they are truly in support of a final plan. More research is needed into partners' satisfaction with births both inside and outside the system.

References

1) Singh D, Newburn M. Becoming a father: men's access to information and support about pregnancy, birth and life with a new baby. London: National Childbirth Trust 2000.
2) Jeffery T, Luo KY, Kueh B, Petersen RW, Quinlivan JA. Australian Fathers' Study: What Influences Paternal Engagement With Antenatal Care? J Perinat Educ. 2015;24(3):181-7.
3) Fenwick J, Bayes S, Johansson M. A qualitative investigation into the pregnancy experiences and childbirth expectations of Australian fathers-to-be. Sex Reprod Healthc. 2012 Mar;3(1):3-9.
4) Locock L, Alexander J. 'Just a bystander'? Men's place in the process of fetal screening and diagnosis. Soc Sci Med. 2006 Mar;62(6):1349-59.
5) Williams RA, Dheensa S, Metcalfe A. Men's involvement in antenatal screening: a qualitative pilot study using e-mail. Midwifery. 2011 Dec;27(6):861-6.
6) Steen M, Downe S, Bamford N, Edozien L. Not-patient and not-visitor: a metasynthesis fathers' encounters with pregnancy, birth and maternity care. Midwifery. 2012 Aug;28(4):362-71.
7) Widarsson M, Engström G, Tydén T, Lundberg P, Hammar LM. 'Paddling upstream': Fathers' involvement during pregnancy as described by expectant fathers and mothers. J Clin Nurs. 2015 Apr;24(7-8):1059-68.
8) Lindberg I, Engström A. A qualitative study of new fathers' experiences of care in relation to complicated childbirth. Sex Reprod Healthc. 2013 Dec;4(4):147-52.
9) Cramer EM. Health Information Behavior of Expectant and Recent Fathers. Am J Mens Health. 2018 Mar;12(2):313-325.
10) Johansson M, Fenwick J, Premberg A. A meta-synthesis of fathers' experiences of their partner's labour and the birth of their baby. Midwifery. 2015 Jan;31(1):9-18.
11) Longworth HL, Kingdon CK. Fathers in the birth room: what are they expecting and experiencing? A phenomenological study. Midwifery. 2011 Oct;27(5):588-94.
12) Dheensa S, Metcalfe A, Williams RA. Men's experiences of antenatal screening: a metasynthesis of the qualitative research. Int J Nurs Stud. 2013 Jan;50(1):121-33.
13) Atkin K, Berghs M, Dyson S. 'Who's the guy in the room?' Involving fathers in antenatal care screening for sickle cell disorders. Soc Sci Med. 2015 Mar;128:212-9.
14) Xue WL, He HG, Chua YJ, Wang W, Shorey S. Factors influencing first-time fathers' involvement in their wives' pregnancy and childbirth: A correlational study. Midwifery. 2018 Jul;62:20-28.
15) Chervenak et al. Planned home birth: the professional responsibility response. Am J Obstet Gynecol. 2013 Jan;208(1):31-8.
16) Hendrix M, Pavlova M, Nieuwenhuijze MJ, Severens JL, Nijhuis JG. Differences in preferences for obstetric care between nulliparae and their partners in the Netherlands: a discrete-choice experiment. J Psychosom Obstet Gynaecol. 2010 Dec;31(4):243-51.
17) Bedwell C, Houghton G, Richens Y, Lavender T. 'She can choose, as long as I'm happy with it': a qualitative study of expectant fathers' views of birth place. Sex Reprod Healthc. 2011 Apr;2(2):71-5.
18) Sweeney S, O'Connell R. Puts the magic back into life: Fathers' experience of planned home birth. Women Birth. 2015 Jun;28(2):148-53.
19) Lindgren H, Erlandsson K. She leads, he follows - fathers' experiences of a planned home birth. A Swedish interview study. Sex Reprod Healthc. 2011 Apr;2(2):65-70.
20) Jouhki MR, Suominen T, Åstedt-Kurki P. Supporting and Sharing-Home Birth: Fathers' Perspective. Am J Mens Health. 2015 Sep;9(5):421-9.
21) Lindgren H, Hildingsson I, Rådestad I. A Swedish interview study: parents' assessment of risks in home births. Midwifery. 2006 Mar;22(1):15-22.
22) Martínez-Mollá T, Solano Ruiz C, Siles González J, Sánchez-Peralvo M, Méndez-Pérez G. The father's decision making in home birth. Invest Educ Enferm. 2015 Dec;33(3):573-583.
23) Perinatal Care in the Netherlands. 2016. https://assets.perined.nl/docs/7935f9c6-eaac-4f59-a150-307ae04efa27.pdf. Accessed 27-03-2018.

24) Hollander M, de Miranda E, van Dillen J, de Graaf I, Vandenbussche F, Holten L. Women's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis. BMC Pregnancy Childbirth. 2017 Dec 16;17(1):423.
25) Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19(6):349–357.
26) Charmaz K. Constructing grounded theory. A practical guide through qualitative analysis. 2nd ed. London: Sage publications; 2007.
27) AMC. Why women want Other or No DElivery caRe. https://www.amc.nl/web/leren/research-62/research/wonder-studie.htm. Accessed 11-09-2018.
28) Viisainen K. Negotiating control and meaning: home birth as a self-constructed choice in Finland. Soc Sci Med. 2001 Apr;52(7):1109-21.
29) Cheyney, M. Home birth as systems-challenging praxis: knowledge, power, and intimacy in the birth place. Qualitative Health Research. 2008: 18,254–267.
30) Boucher, D, Bennett,C, McFarlin, B, Freeze, R. Staying home to give birth: Why women in the United States choose home birth. Journal of Midwifery & Women's Health. 2009: 54,119–126.
31) Murray-Davis, B, McNiven, P, McDonald, H, Malott, A, Elarar, L, Hutton, E. Why home birth? A qualitative study exploring women's decisionmaking about place of birth in two Canadian provinces. Midwifery. 2012:28,576–581.
32) Miller, A. Midwife to myself: Birth narratives among women choosing unassisted home birth. Sociological Inquiry. 2009:79,51–74.
33) Dejoy S. The role of male partners in childbirth decision making: a qualitative exploration with first-time parenting couples. Dissertation. University of south Florida 2011.
34) Ryding EL, Read S, Rouhe H, Halmesmäki E, Salmela-Aro K, Toivanen R, Tokola M, Saisto T. Partners of nulliparous women with severe fear of childbirth: A longitudinal study of psychological well-being. Birth. 2018 Mar;45(1):88-93.
35) Hildingsson I, Cederlöf L, Widén S. Fathers' birth experience in relation to midwifery care. Women Birth. 2011 Sep;24(3):129-36.
36) Dutch Civil Law, book 7, article 446.
37) Draper H, Ives J. Men's involvement in antenatal care and labour: rethinking a medical model. Midwifery. 2013 Jul;29(7):723-9.
38) Holten L, Hollander M, de Miranda E. When the hospital is no longer an option: a multiple case study of defining moments for women choosing home birth in high-risk pregnancies in the Netherlands. Qual Health Res. 2018 Oct;28(12):1883-1896.
39) Osamor PE, Grady C. Autonomy and couples' joint decision-making in healthcare. BMC Med Ethics. 2018 Jan 11;19(1):3.
40) The SHARE approach- Essential Steps of Shared Decisionmaking: Quick Reference Guide. https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-1/index.html. Accessed 10-9-2018.

6

Less or more?
Maternal requests that go against medical advice.

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Abstract

Problem and background
This study explores the experiences of Dutch midwives and gynaecologists with pregnant women who request more, less or no care during pregnancy and/or childbirth.

Methods
All Dutch midwives and (trainee) gynaecologists were invited to fill out a questionnaire specifically designed for the purposes of this study. Holistic midwives were analysed separately from regular community midwives.

Findings
Most maternity care providers in the Netherlands receive requests for less care than recommended at least once a year.) The most frequently maternal requests were declining testing for gestational diabetes (66.3%), opting for a home birth in case of a high risk pregnancy (65.3%), and declining foetal monitoring during labour (39.6%). Holistic midwives are more convinced of an increasing demand for less care than community midwives (73.1% vs. 35.2%, p=<0.001). More community midwives than hospital staff reported to have declined one or more request for less care than recommended (48.6% vs. 27.9%, p=<0.001 The majority of hospital staff also receive at least one request for an elective caesarean section every year.

Discussion and conclusion
Requests for more and less care than indicated during pregnancy and childbirth are equally prevalent in this study. However, a request for less care is more likely to be declined than a request for more care. Counselling women who disagree with their care provider demands time. In case of requests for less care, second best care should be considered.

Introduction

In recent years, there have been signs that an increasing number of Dutch pregnant women are choosing a level of maternity care based on their personal preferences rather than as prescribed by national guidelines and the advice of health professionals. This phenomenon is not unique to the Netherlands. A growing list of publications from different countries examines women's motivations for refusing recommended care during pregnancy and/or childbirth.[1, 2, 3, 4, 5, 6] This research encompasses women with a high risk pregnancy who choose to give birth at home attended by a midwife, and women who choose to give birth unattended (unassisted childbirth/UC). Publications about the opposite, women requesting more care than indicated, also seem to be increasing, with a growing number of articles examining the phenomenon of caesarean delivery at maternal request (CDMR).[7, 8] However, there is a paucity of data about the experiences of midwives and gynaecologists with women who decline recommended care during pregnancy and childbirth, with the exception of women declining an emergency caesarean section.[9, 10, 11, 12]

In the past five years, declining recommended care has been a hotly debated subject in Dutch maternity care, inspiring many conferences, workshops and symposia, and even resulting in a new national guideline for maternity care providers on how to cope with these refusals.[13] Whether refusals are truly increasing or if this is merely the personal impression some providers have, based on certain reported cases and growing publicity, is thus far unknown.

The WONDER-study (Why women want Other or No DElivery care) is a mixed methods study exploring the phenomenon of birth choices against medical advice in the Netherlands. The qualitative part consists of studies examining the motivations of women who elected to go against medical advice in their choice of place of birth and/or birth attendant,[6] and those of their partners and their caregivers. The WONDER-study also contains a literature review on women's motivations[14] and a commentary on legal and ethical perspectives.[15] The quantitative part is the subject of this paper. This study explores the experiences of Dutch midwives and gynaecologists with pregnant women who request more, less or no care during pregnancy and/or childbirth. We analyzed whether maternity care providers perceived an increase in these requests, what type of requests they received during antenatal checks and if this differed between levels of care. We were also interested in why and how often requests were granted or declined, the willingness to refer to a colleague and the extra time spent on counselling the women concerned. Finally, we examined the differences in experience and attitude regarding this topic between

community midwives and ("holistic") midwives who are willing to assist during a home birth in a high risk pregnancy.

Participants, ethics and methods

Questionnaire

An anonymous questionnaire specifically designed for the purposes of this study was made available online through Survey Monkey. The questionnaire contained 33 items: nine questions on demographic data and type of practice, fifteen on personal experience with requests for either more or less care than indicated. Nine statements with Likert scales reflecting the attitude of caregivers towards requests for less or more care were incorporated with the purpose to describe the results in a separate paper, because the extensiveness of these results would not justify discussion within the context of one article. The questionnaire remained online for approximately nine weeks in the autumn of 2015.

Setting and participants

An attempt was made to reach all registered, practicing obstetrician–gynaecologists and midwives in the Netherlands. To this end, an email with the request to participate was sent to all (trainee) members of the Dutch Society of Obstetrics and Gynaecology (NVOG), of which virtually every practicing gynaecologist and trainee in OB/GYN in the country is a member (N = 1408). After two weeks a reminder was sent through the same channels. Midwives were approached through the Royal Dutch Organization of Midwives (KNOV), who included the request to participate in the "call" section of their monthly newsletter. Not all practicing Dutch midwives are members of this organization (N = 2733, 2304 community midwives and 429 clinical midwives) and the "call" section of the newsletter is not very well read. Therefore, the request to participate and disseminate the link to the survey was also sent to all regional organized groups of midwives and to hospital-based midwives who are members of an NVOG working group for clinical midwifery. There is a small group of midwives active in the Netherlands who are willing to assist women with a high risk pregnancy during a home birth, who we qualified in this study as "holistic midwives". Their actual number is unknown, but self-reported to be in the range of 20–30, depending on which definition is used. For the purposes of this questionnaire, we asked community midwives who participated to label themselves as "midwife in regular practice" or "holistic midwife". These two groups will from here on be referred to as "community midwives" and "holistic midwives". Many holistic midwives are not part of any professional organization.

Therefore the link to our survey was also posted on the closed facebook page of a group of holistic midwives (N = 23 at the time of the survey).

Holistic midwives in the Netherlands often work solo or in couples (case-load). In order to be able to provide one-on-one continuity of care, they usually only accept a handful of clients per month. Most of them started out in group practices, but found themselves at odds with their colleagues when they discovered they wanted to comply with women who declined certain protocollized care (less care).

Since the aim of the study was to gain insight in practitioners' experiences and opinions, the following participants were excluded from analysis due to insufficient (recent) clinical experience: newly qualified doctors without a training post, trainee midwives, and retirees or those no longer working in patient care.

Ethical approval was deemed not necessary by the ethics committee of the Radboud University of Nijmegen (autumn of 2015).

Sample size

The sample size was calculated using the following formulas:

Sample Size = (Distribution of 50%)/((Margin of Error 5%/Confidence Level 95%) Squared)

Finite population correction:

True Sample = (Sample Size × Population)/(Sample Size + Population − 1)

For a representative sample we needed responses from 329 community midwives and 330 hospital staff (clinical midwives and (trainee) gynaecologists).

Analysis

Data were analyzed in SPSS version 22 (IBM Corporation Inc., Armonk, NY, USA) and free text fields were recoded into existing categories or made into new ones. Responses were compared according to level of care; community midwives versus hospital staff (trainee gynaecologists, gynaecologists and clinical midwives). A separate analysis was performed to determine any differences between community midwives and holistic midwives, since it was expected that holistic midwives would have different opinions and different (more) experience relative to the subject in question, due to their role as "last resort" for women with requests for less care.

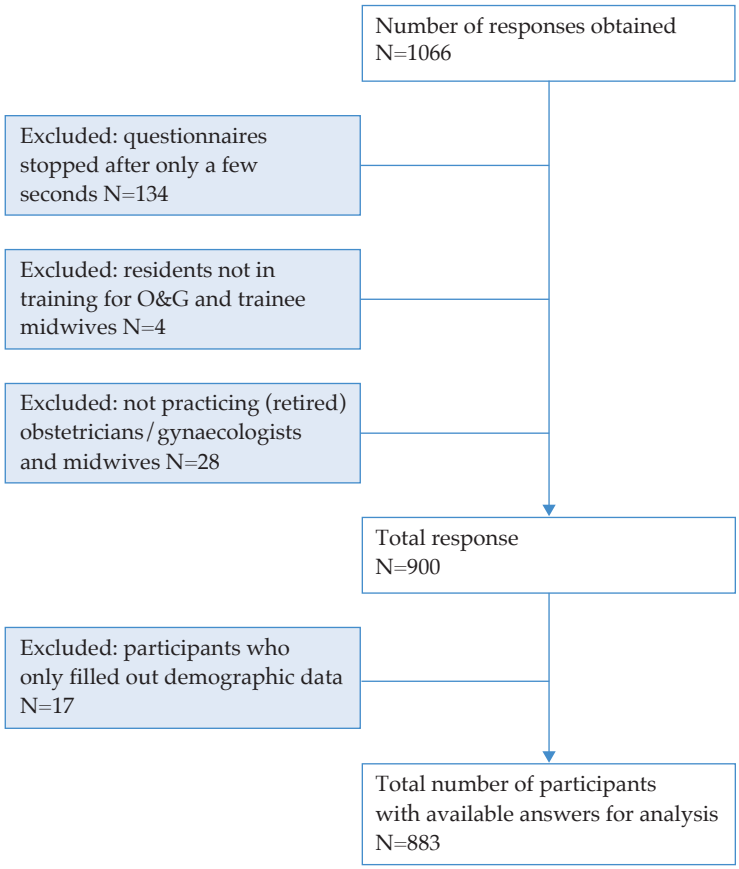
Chi-square tests were used to analyze categorical variables, and ordinal variables were analyzed using Mann–Whitney U tests. A p-value of <0.05 was considered significant.

Results are divided into three sections. Responses in "Less care than indicated" and "More care than indicated" were compared between hospital staff and community midwives. A third section is devoted to differences between community midwives and holistic midwives.

Results

Of 1066 questionnaires, 134 were excluded due to incomplete data, four responses were from recently graduated doctors without an OB/GYN training post and 28 responses from retirees or those who were no longer working in patient care.

Figure 1 Responses and exclusions



This left 900 questionnaires, for a total response rate of 21.7%, assuming all (trainee) gynaecologists and all practicing midwives with a KNOV membership were reached. When divided by level of care the response was 455 (19.7%) for community midwives, and 445 (24.2%) for hospital staff (gynaecologists, trainees and clinical midwives). Seventeen responses contained only demographic data and were excluded from further analysis. This left 883 questionnaires for final analysis (Fig. 1). We needed 329 completed questionnaires from community midwives and 330 from hospital staff. Therefore, the response can be considered as representative for the groups being studied.

Table 1 shows the characteristics of the participants. Eighty-eight percent of participants were female, with 40% of participants between 30 and 40 years old and 18% over the age of 50. More than half of the participants had 10 or more years of work experience.

Table 1 Characteristics of participants (N = 900)

Characteristics	Participants N=(%)
Gender	
- Male	108 (12.0)
- Female	792 (88.0)
Age (years)	
- <30	174 (19.3)
- 31-40	357 (39.7)
- 41-50	204 (22.7)
- 51-60	129 (14.3)
- >60	36 (4.0)
Profession	
- Community midwife	455 (50.6)
• Regular community midwife	429 (47.9)
• Holistic midwife	26 (2.7)
- Hospital based midwife (secondary care)	113 (12.6)
- Gynaecologist	239 (26.6)
- Resident O&G	93 (10.3)
Work experience (years)	
- 1-2	61 (6.9)
- 3-5	135 (15.0)
- 6-10	215 (23.9)
- 10-20	274 (30.4)
- >20	199 (22.1)
- Missing	16 (1.8)

Less care than indicated

The first part of the questionnaire addressed the participants' personal experience with pregnant women requesting less care than indicated during pregnancy and birth.

A minority of both midwives and gynaecologists experienced an increase in women with high risk pregnancies wanting a home birth over the last five years. Community midwives were less convinced this phenomenon had increased over the last five years than hospital staff (35.2% vs. 45.7%, p = <0.001). Of the community midwives, 88.9% had received a request for less care in the year before the survey, versus 83.5% of hospital staff (p = 0.03). There was no difference between caregivers with more than 10 years or less than or equal to 10 years of experience in maternity care.

The most frequently mentioned maternal requests were declining testing for gestational diabetes (66.3%), opting for a home birth in case of a high risk pregnancy (65.3%), and declining foetal monitoring (both continuous and intermittent) during labour (39.6%). Hospital staff reported significantly more declining foetal monitoring, assisted vaginal birth (ventouse or forceps) and caesarean section, and community midwives reported significantly more requests for home birth in high risk pregnancies, declining diabetes testing, and women planning UC (Table 2). However, only a small minority of participants in both levels of care reported to have received any of the requests mentioned above more than twice in the previous year, with the exception of declining diabetes testing, which was quite prevalent.

The most frequently given medical reasons for recommending hospital birth in women requesting home birth against medical advice concerned a high body mass index (BMI) (41.8%), post term pregnancy (36.7%) and a previous caesarean section (32.9%). Hospital staff significantly more often received requests for home birth from women with a previous caesarean section and women who had a breech position or a twin pregnancy, whereas community midwives were significantly more often confronted with requests for home birth in case of a high BMI (Table 3). Very few participants encountered more than five of any of these requests in that year, and no participants had received more than five requests for a home breech- or twin birth in the previous year.

Significantly more community midwives than hospital staff reported having declined one or more request for less care than recommended: 48.6% vs. 27.9% (p = <0.001). On average between both hospital staff and community midwives, 39.6% declined at least one request for less care. Most frequently indicated reasons for declining by both levels of care were "want to have intervention possibilities if necessary" and "don't want to be (morally) responsible for a bad outcome". Other reasons were "harmful for interdisciplinary cooperation", "not

Table 2 Nature of requests for less care according to participants

Request[a]	Regular community midwives (%)	Hospital staff (%)	p-value
Wanting home birth in high risk pregnancy	72.5	57.3	<0.001*
Refusal of diabetes testing	77.1	54.2	<0.001*
Refusal of foetal monitoring	28.6	51.2	<0.001*
Refusal of assisted vaginal delivery	21.9	48.0	<0.001*
Wanting unassisted childbirth	18.1	11.8	0.03
Refusal of indicated caesarean section	10.8	26.5	<0.001*

[a]Rare refusals (mentioned less than five times in the free text fields) were labour augmentation, pelvic exams, active management of the third stage, manual placental removal, routine lab testing, routine ultrasounds, doptone during antenatal checks, number of routine antenatal checks, biometric ultrasound for suspicion of IUGR or macrosomia, indicated antibiotic prophylaxis, episiotomy, vitamin K, PKU testing for the neonate and precautionary iv access during labour.
*Significant difference

feeling competent", "fear for legal repercussions" and "fear of reputation damage". There was a significant difference regarding fear for legal repercussions between community midwives and hospital staff (30.3% vs. 9.5%, $p < 0.001$).

In cases where requests for less care are not honoured by the caregiver, referral to a colleague is possible. Significantly more community midwives than hospital staff have availed themselves of this option at least once (48.0% vs. 23.1%, $p = <0.001$). When seriously concerned for the health of the unborn child, some participants reported a pregnant woman to child protective services—which has no legal justification in Dutch law-, although incidences of this were low and not significantly different between community midwives and hospital staff (1.8% vs. 2.5%, $p = 0.52$).

A third (36.2%) of the participants, community midwives as well as hospital staff, reported that consultations with women requesting less care than indicated took up on average 15–30 min extra time. Another third (33.9%) spent more than 30 min of extra time discussing such a request, and for five percent it took even more than 60 min extra.

A small and comparable minority of both community midwives and hospital staff indicated having performed pregnancy checks on women who planned a UC in the previous year (12.7% vs. 9.7%, $p = 0.17$). Among community midwives, 9.6% reported that they had been called to assist during or after a planned UC at least once, vs. 6.2% of hospital staff who had received UC women

Table 3 Requests for home delivery according to the indication for secondary care

Indication[bc]	A: Community midwives N (%)	B: Hospital staff N (%)	C: Holistic midwives[d] N (%)	p-value (between A and B)	p-value (between A and C)
BMI>40	198 (48.4)	123 (34.1)	13 (61.9)	<0.001*	0.34
Post term pregnancy	157 (38.5)	123 (34.4)	18 (85.8)	0.49	<0.001*
Previous caesarean section	111 (27.2)	124 (38.8)	16 (76.2)	<0.001*	<0.001*
Ruptured membranes >24 hrs	118 (29.1)	85 (23.7)	13 (61.9)	0.18	<0.001*
Previous PPH > 2 litres	77 (19.1)	71 (19.7)	8 (38.1)	0.98	0.02*
Hypertensive disorders	48 (11.9)	61 (17.0)	11 (52.4)	0.13	0.11
Preterm delivery	49 (12.3)	35 (9.8)	11 (52.4)	0.28	<0.001*
Breech birth	8 (2.0)	34 (9.5)	9 (39.1)	<0.001*	<0.001*
Diabetes requiring insulin	11 (2.8)	15 (4.2)	3 (N/A)	0.52	N/A
Twin birth	5 (1.2)	18 (5.0)	2 (N/A)	<0.001*	N/A
Declined requests for home delivery in case of at least one of the above indications	201 (48.6)	105 (27.9)	16 (66.7)	<0.001*	0.08
Been called for help with an UC	39 (9.6)	26 (6.2)	6 (28.6)	0.07	0.01*

[b]Rare indications (mentioned less than five times in the free text fields) were IUGR, Jehovah's Witness, positive culture for GBS
[c]Twin birth and diabetes requiring insulin were too rare in the group of holistic midwives to calculate.
[d]Midwives who classified themselves as working in a holistic setting
*Significant difference

in their clinic (p = 0.07). Reported reasons for being consulted were "complications during birth" (46.8%), "postpartum check requested" (29.0%) and "woman changed her mind" (24.2%).

More care than indicated

The second part of the questionnaire involved CDMR. One or more requests for CDMR in the previous year were reported by 88.1% of hospital staff and 79.7% of community midwives (p < 0.001). Of hospital staff, 75.6% indicated that such requests have increased in the past five years, and 71.7% of those who received one or more requests for CDMR honoured at least one, with 28.3% refusing all such requests.

Almost half (44.8%) of participants reported that consultations with women requesting a CDMR took up 15–30 min extra time, a quarter (26.8%) needed more than 30 min extra, and 2.4% took more than 60 min of extra time.

Most important reasons (more options possible) for CDMR according to both community midwives and hospital staff were "Fear of vaginal birth" (93.8% vs. 96.2%), "Fear of pain" (68.4% vs. 68.0%), "Autonomy" (41.1% vs. 49.3%), "Concern for foetal health"(33.8% vs. 47.2%), "Fear of pelvic floor damage" (31.8% vs. 29.7%) and "Practical reasons" (24.0% vs. 26.8%). The options "Autonomy" and "Concern for foetal health" were filled out more frequently by hospital staff (p = 0.01 and p = <0.001).

Holistic midwives

Twenty-six midwives classified themselves as "holistic". According to several of them, this comprised the majority of those who were active in this setting in the Netherlands at the time of the survey. Seventy-two percent of holistic midwives reported that they regularly provide care outside guidelines/protocols on maternal request, which means they regularly attend home births in high risk pregnancies. The other 28% do so more rarely. Holistic midwives received more requests for home birth in high risk pregnancies than community midwives for all indications, the most prevalent of which were post term pregnancy (85.8% vs. 38.5%, p = <0.001), previous caesarean section (76.2% vs. 27.2%, p = <0.001) and prolonged (>24 h) ruptured membranes (61.9% vs. 29.1%, p = <0.001) (Table 4).

Holistic midwives have had more clients who planned a UC than community midwives (38.1% vs. 12.7%, p = <0.001), and they were also more often called on to assist during a planned UC (28.6% vs. 9.6%, p = 0.01).

Holistic midwives were much more concerned for legal repercussions than community midwives after delivering care outside guidelines or protocol (44.4% vs. 8.5%, p = <0.001). However, only seven of them (27%) reported that concern for legal repercussions has prompted them at least once to decline the requested

Table 4 Rate of midwives receiving requests for home birth according to indication for secondary care

Indication[c]	Holistic midwives[d] (%)	Community midwives (%)	p-value
Post term pregnancy	85.8	38.5	<0.001*
Previous caesarean section	76.2	27.2	<0.001*
BMI>40	61.9	48.5	0.34
Prolonged (>24 hours) ruptured membranes	61.9	29.1	<0.001*
Preterm delivery	52.4	12.3	<0.001*
Hypertensive disorders	52.4	23.8	0.11
Breech birth	39.1	2.0	<0.001*
Previous post partum hemorrhage > 2 liters	38.1	19.1	0.02*

[c]Twin birth and diabetes requiring insulin were too rare to calculate.
[d]Midwives who classified themselves as working in a holistic setting
*Significant difference

care. More holistic midwives than community midwives have declined a request for less care than indicated at least once (66.7% vs. 48.6%, p = 0.08), although this is a non significant difference, most likely due to small numbers. They are also more convinced of an increasing demand for such care than community midwives (73.1% vs. 35.2%, p = <0.001).

Compared to community midwives, holistic midwives spend more extra time on counselling women who request less care than recommended: a third spend more than an hour longer compared to 6.6% of the community midwives.

Discussion

It is not very well known how often maternity care providers actually encounter a pregnant woman who declines a recommended procedure or place of birth, and how they manage this situation. In this nationwide survey, we found that more than 80% of caregivers received at least one request for less care than advised in the preceding year. Furthermore, almost 90% of gynaecologists had encountered a request for CDMR in the preceding year. Finally, almost 75% of holistic midwives regularly work outside protocols.

In interpreting these data, it is important to realise that the societal position of medical professionals has changed. Unlike in previous times, shared decision making and informed consent should by now have become the norm, as recommended in all recent professional guidelines. This should certainly apply in maternity care, where pregnant women have become critical health care consumers, who no longer automatically accept the advice of their caregiver. Instead, they are less accepting of a "one size fits all" approach and more inclined to decide for themselves which (level of) care they desire.[16, 17]

With the requirement of informed consent comes the option of informed refusal. In certain fields of medicine, there is ample experience with patients who decline treatment for themselves, for instance in oncology.[18] This is usually accepted by medical professionals in accordance with the ethical principle of autonomy. However, when pregnant women decline the recommended policy, midwives and gynaecologists often feel that optimal care is declined for the child, and this can cause conflict between the pregnant woman and her care provider.[15] This situation is often referred to as maternal–foetal conflict[19] and has, in several other countries, notably the United States, led to care providers resorting to a court-ordered caesarean section.[20, 21] The justification given in those circumstances for not honouring a pregnant woman's informed refusal of a recommended intervention or place of birth is a danger to the health of the child in utero, since caregivers believe that the woman's refusal of the proposed intervention poses an acute danger to her child. In such instances, care providers are convinced that honouring the woman's refusal will or may very likely lead to damage to or death of the child. In these situations, care providers place a higher value on the ethical principle of beneficence (to the child) than autonomy (of the mother).

In the Netherlands, there are no legal grounds for overriding a competent adult's refusal, hence there have been no court-ordered caesareans here to date. In Dutch law, a child does not legally exist before it has been born, and therefore has no enforceable rights before birth. However, it does have a moral right to have its wellbeing protected, which becomes stronger with increasing gestational age. Dutch jurisprudence has always let maternal autonomy and her right to bodily integrity prevail over the child's right to protection of its wellbeing. The high value attached to maternal autonomy in Dutch society could also form part of the explanation for the increase in acceptance of CDMR (autonomy) over not doing unnecessary harm to the woman's body (non-malificence).

To date, no studies have been done linking a previous traumatic experience in childbirth to either declining care or a CDMR in the next pregnancy. However, a recent qualitative study by this same group as part of the WONDER-study interviewed 28 women who chose to have a home birth in a high risk pregnancy

or a UC.[6] Most of them mentioned a traumatic experience during a previous birth as contributing to their decision to accept less care than recommended. Traumatic childbirth experiences unfortunately are quite common, and insight into their causes could aid professionals in their attempts to provide conditions for better birth experiences.[22] It would therefore seem to be a worthwhile approach for caregivers to explore the reasons behind a woman's request for less care, in addition to trying to prevent the initial trauma during the first birth.

Less care

The perception of many regular maternity care providers in the Netherlands that there is a trend toward an increase of maternal requests for less care could not be confirmed in this study. However, most participants had personal experience with women who declined (part of) the indicated and offered care. Community midwives were less often convinced that refusals were increasing than hospital staff. This could be explained by the fact that most interventions take place in a hospital setting, where there is simply more to decline. In cases of declining hospital birth for a high risk pregnancy, the more serious indications (previous caesarean section, breech and twin pregnancies) were more often encountered in a hospital setting than in the practice of a community midwife, whereas midwives encountered more requests for home births from women with a BMI over 40. Interestingly, significantly more community midwives reported declining a request for less care than hospital staff. This could be explained by the fact that community midwives can refer both to the hospital and to a holistic colleague, whereas hospital staff may believe they are the last avenue of recourse and are not accustomed to refer women to community or holistic midwives in case they are unable to reach an agreement. If hospital staff decline a request for less care, they may believe most if not all women will go along with the proposed standard treatment regimen, although some women will in actuality feel that the only option left to them is to turn to UC, or to a holistic midwife6. However, community midwives did not give any different reasons for declining requests than hospital staff did, with the noticeable exception of fear of legal repercussions, which is well known to be a factor in the increase of defensive medicine.[23] Finally, a minority of participants had come into contact with the phenomenon of UC. In the absence of any official records, the best guess of the incidence of UC in the Netherlands is around 200 cases per year.[24] The most common reason for the participants to be consulted was the occurrence of unexpected complications. Since there is no registration, it is impossible to say if UC is increasing, or even how long it has been around. However, there are indications that knowledge of the existence of UC as a birth option has increased through the availability of the internet (for instance unas-

sistedchildbirth.com/birthwithoutfearblog.com/trustbreathebirth.com.au). UC could be considered as a counter movement of women who reject institutionalized maternity care and the biomedical model.[2, 4]

More care

There is a variety of requests for more care than indicated, such as elective induction of labour, prenatal care and birth in secondary care without an indication, non medically indicated ultrasound scans and CDMR.[25] Many of these requests have become so common that they are not even registered as being against guidelines. For the purposes of this study we focused on CDMR, since most providers still consider an operation without indication on a healthy woman as an increased risk option which should not be honoured without (a certain measure of) discussion and counselling.[7] Other requests for more (elective) care are even more prevalent than CDMR and will meet with less opposition from providers.[25]

Approximately the same percentage of hospital staff that reported a request for less care (83.5%), received one or more requests for CDMR (88.1%). Hospital staff was also more convinced of an increase in CDMR (75.6%) than of an increase in declining recommended care (45.7%). This is in line with current trends in the Netherlands, where an increasing number of women are opting for elective obstetrical care such as use of an epidural or birth in secondary care without medical reason.[26]

Almost seventy-two percent of hospital-based participants who received one or more requests for CDMR honoured at least one. It appears that getting a non medically indicated caesarean section has become easier for women in the Netherlands in the past decade. In a nationwide survey by Kwee et al.[7] in 2004, two entirely elective fictitious cases were proposed to the participants. Only between 19 and 24% of obstetricians were willing to comply with a CDMR in that year, which fits with the increasing trend of medicalisation of childbirth in recent decades.[27]

When pregnant women decline certain interventions, an often heard complaint involves the burden of extra time it takes to counsel them. This study shows, however, that providers need approximately an equal amount of extra time counselling women who decline recommended care, as they need to counsel women who request a CDMR.

Holistic midwives

Women have found their way to holistic midwives, as demonstrated by the fact that 72% of holistic midwives reported receiving these refusals regularly, and strengthened by the fact that more holistic midwives (73.1%) than community

midwives (35.2%) are convinced requests for less care are increasing. Even though most do not advertise the way they work, holistic midwives can be easily found by women through social media and client platforms, when a woman's request for less care has been declined by her provider.[6] The previously mentioned professional guideline on dealing with requests for less care[13] counsels providers to refer a pregnant woman to a colleague if they are unable to reach an agreement regarding the requested care. Holistic midwives are often the only providers willing to take these women on, thereby helping obstetricians and community midwives to fulfil their obligation to find another carer.

Because most of them work on a case-load basis, accepting only a few clients per month, holistic midwives have (or take) much more time to counsel women who request a home birth in a high risk pregnancy than community midwives, with 75% taking at least 30 min of extra time, and the other 25% taking over an hour more. Understandably, all requests for home birth in a high risk pregnancy as well as UC were more prevalent among holistic midwives, and they were also more often consulted during an ongoing UC. It also stands to reason that many of the clients who were declined and referred by their community midwife for requesting less care than recommended were referred to a holistic midwife, since that request was more likely to be honoured there.

The holistic midwives in this survey reported being more afraid of the legal repercussions of assisting in a high risk home birth or UC than community midwives. However, only a minority has declined a request for less care because of this fear.

Holistic midwives' fear for legal repercussions could be caused by a highly publicized court trial in 2013, where three midwives were disciplined for assisting in several high risk home births.[28] One of these involved a breech birth, and two were twin births. Ultimately, one midwife lost her license, but the verdict was later overturned by a higher court, citing women's right to choose their own place of giving birth, and acknowledging the fact that any support (of a maternity care provider) in those situations is better than none (UC). Nonetheless, this may have caused a certain measure of caution in holistic Dutch midwives, although the majority has not changed her practice.

Strengths and limitations

There are some limitations to the study. First, the total response rate was 21.7%, which appears rather low. However, more responses were collected than were needed according to the sample size calculation. In addition, there is the likelihood that, despite best efforts, not all members of the target population were reached, since the call section of the newsletter from the organization of midwives is not very well read, which is a known problem. Therefore it could

well be that the percentage of community midwives who both read and replied to our invitation is actually significantly higher than 19.7%, thereby increasing the total response rate. Finally, medical professionals receive a large number of questionnaires on a monthly basis. It is therefore to be expected that response rates are not high due to "survey fatigue".

A second limitation could be the possibility of recall bias. Some questions in the survey specifically enquired into contacts with pregnant women during the year prior to filling out the questionnaire. Faulty recall could have led to both under- and overestimation. However, for most caregivers it concerned special cases which tend to leave a lasting impression.[29]

The main strength of this study is the fact that it is the first to report how often medical professionals in the Netherlands, a country known for its physiological approach to childbirth, receive requests for more or less maternity care, and how they deal with such requests. It is also the first time there is a record of how often maternity care providers are confronted with women who desire a home birth in case of a high risk pregnancy, and which high risk situations these are.

Another strength of this study is that it reports on the practice and experiences of holistic midwives working in a country were the maternity care system accepts home birth for low risk women as a regular option and where low risk women can choose to deliver at home, in a birth centre or in a hospital.

Implications for practice

Most maternity care providers will encounter pregnant women who request care that goes against medical advice. In those situations, as in others, shared decision making should be the norm. Counselling women who disagree with their care provider demands time, interest and conversational skills. It also requires a joint effort between primary and secondary care providers. A designated multi-disciplinary clinic, where community midwives and hospital staff together see women who have requests that go against recommendations, is worth considering. In case of persistent requests for less care, second best care (in the opinion of the providers) should be considered. Second best care in this context could for instance be a hospital birth after a previous caesarean section but without (or with limited) foetal monitoring, or a home birth after 42 completed weeks of pregnancy. Allowing this as second best care could prevent women from choosing a solution that poses even more risk to them and their baby, like electing to attempt a UC.

Conclusion

The vast majority of maternity care providers in the Netherlands are, at least once a year, confronted with requests for less care than recommended according to guidelines and protocols. This ranges from declining glucose tolerance testing to home birth in a high risk pregnancy or even unassisted childbirth. A comparable percentage of hospital staff receive at least one request for a non-medically indicated caesarean section every year. Refusing requests for less care is common, especially by community midwives, who in that case often refer to either the hospital, or to a colleague who is prepared to provide care outside the guidelines, as is recommended in the recently developed multidisciplinary Dutch national guideline "Maternity care outside guidelines".[13]

Although 40% of maternity care providers in the Netherlands (with the exception of holistic midwives) experienced an increase in requests for home births in high risk pregnancies, a majority saw no increase in these requests. However, they indicated getting more requests for non-medically indicated caesarean sections now than ten years ago.

The majority of Dutch maternity care providers spend at least 15–30 min more time on counselling women who decline the recommended policy, and an equal amount of extra time on women who desire a caesarean section without a medical reason.

In conclusion, considering the physiological approach to childbirth that the Netherlands is known for, requests for both more and less care than indicated during pregnancy and childbirth are about equally prevalent. In this study, 39.6% of hospital and community maternity carers (with the exception of holistic midwives) declined at least one request for less care, while only 28.3% of hospital staff declined all CDMR. Therefore, a request for less care is more likely to be declined than a request for more care.

References

1) M. Jackson, H. Dahlen, V. Schmied. Birthing outside the system: perceptions of risk amongst Australian women who have freebirths and high risk home-births. Midwifery, 28 (2012), pp. 561-567.
2) C. Feeley, E. Burns, E. Adams, G. Thomson. Why do some women choose to freebirth? A meta-thematic synthesis, part one. Evid Based Midwifery, 13 (2015), pp. 4-9.
3) C. Feeley, G. Thomson. Why do some women choose to freebirth in the UK? An interpretative phenomenological study. BMC Pregnancy Childbirth, 16 (2016), p. 59.
4) L. Holten, E. de Miranda. Women's motivations for having UC or high-risk homebirth: an exploration of the literature on 'birthing outside the system'. Midwifery, 38 (July) (2016), pp. 55-62.
5) M. Plested, M. Kirkham. Risk and fear in the lived experience of birth without a midwife Midwifery, 38 (July) (2016), pp. 29-34.
6) M. Hollander, E. de Miranda, J. van Dillen, I. de Graaf, F. Vandenbussche, L. HoltenWomen's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis. BMC Pregnancy Childbirth, 16 (2017), p. 17.
7) A. Kwee, B.J. Cohlen, H.H. Kanhai, H.W. Bruinse, G.H. Visser. Caesarean section on request: a survey in The Netherlands. Eur J Obstet Gynecol Reprod Biol, 113 (April (2)) (2004), pp. 186-190.
8) A. Kalstrøm, R. Engstrøm-Olofsson, A. Nystedt, J. Thomas, I. Hildingsson. Swedish caregivers' attitudes towards caesarean section on maternal request. Women Birth, 22 (June (2)) (2009), pp. 57-63.
9) M. Danerek, K. Marsal, M. Cuttini, G. Lingman, T. Nilstun, A.K. Dykes. Attitudes of midwives in Sweden toward a woman's refusal of an emergency caesarean section or a caesarean section on request. Birth, 38 (March (1)) (2011), pp. 71-79.
10) M. Cuttini, M. Habiba, T. Nilstun, S. Donfrancesco, M. Garel, C. Arnaud, et al. Patiënt refusal of emergency caesarean delivery: a study of obstetricians' attitudes in Europe. Obstet Gynecol, 108 (November (5)) (2006), pp. 1121-1129.
11) C.O. Chigbu, C.C. Ezenyeaku, E. Ezenkwele. Obstetricians' opinions and attitudes toward maternal refusal of recommended caesarean delivery in Nigeria. Int J Gynaecol Obstet, 105 (June (3)) (2009), pp. 248-251.
12) B. Jenkinson, S. Kruske, S. Kildea. The experiences of women, midwives and obstetricians when women decline recommended maternity care: a feminist thematic analysis. Midwifery, 52 (May) (2017), pp. 1-10.
13) KNOV and NVOG. Leidraad Verloskundige zorg buiten richtlijnen, 2015. Retrieved from http://nvog-documenten.nl/uploaded/docs/KNOV%20en%20NVOG%20Leidraad%20Verloskundige%20zorg%20buiten%20richtlijnen%20ek.pdf. [Accessed 1 May 2017].
14) L. Holten, E. de Miranda. Women's motivations for having unassisted childbirth or high risk homebirth: an exploration of the literature on 'birthing outside the system'. Midwifery, 38 (2016), pp. 55-62.
15) M. Hollander, J. van Dillen, T. Lagro-Janssen, E. van Leeuwen, W. Duijst, F. Vandenbussche. Women refusing standard obstetric care: maternal-foetal conflict or doctor-patient conflict? J Preg Child Health, 3 (2016), p. 2.
16) M.J. McIntyre, K. Francis, Y. Chapman. National review of maternity services 2008: women influencing change. BMC Pregnancy Childbirth, 11 (July) (2011), p. 53.
17) G. Thomson, F. Dykes, G. Singh, L. Cawley, P. Dey. A public health perspective of women's experiences of antenatal care: an exploration of insights from a community consultation. Midwifery, 29 (March (3)) (2013), pp. 211-216.
18) I. Madjar, L. Kacen, S. Ariad, J. Denham. Telling their stories, telling our stories: physicians' experiences with patients who decide to forgo or stop treatment for cancer. Qual Heath Res, 17 (April (4)) (2007), pp. 428-441.
19) I. Ohel, A. Levy, M. Mazor, A. Wiznitzer, E. Sheiner. Refusal of treatment in obstetrics—a maternal–foetal conflict. J Matern Fetal Neonatal Med, 22 (July (7)) (2009), pp. 612-615.
20) A. Cherry. The detention, confinement, and incarceration of pregnant women for the benefit of fetal health. Research paper 07–139, Cleveland-Marshall College of Law (2007).

21) T.-A. Samuels, H. Minkoff, J. Feldman, A. Awonuga, T. Wilson. Obstetricians, health attorneys, and court-ordered caesarean sections. Women's Health Issues (17) (2007), pp. 107-114.
22) M. Hollander, E. van Hastenberg, J. van Dillen, M. van Pampus, E. de Miranda, C. Stramrood. Preventing traumatic childbirth experiences: 2192 women's perceptions and views. Arch Women's Ment Health, 20 (August (4)) (2017), pp. 515-523.
23) M. Garcia-Retamero, M. Galesic. On defensive decision making: how doctors make decisions for their patients. Health Expect, 17 (October (5)) (2014), pp. 664-669.
24) A. Verbeek. Baren buiten het boekje. Tijdschrift voor Verloskundigen, 2013 (2013), pp. 40-44.
25) B. Coulm, B. Blondel, S. Alexander, M. Boulvain, C. Le Ray. Elective induction of labour and maternal request: a national population-based study. BJOG, 123 (December (13)) (2016), pp. 2191-2197.
26) P.M. Offerhaus, C. Geerts, A. de Jonge, C.W. Hukkelhoven, J.W. Twisk, A.L. Lagro-Janssen. Variation in referrals to secondary obstetrician-led care among primary midwifery care practices in the Netherlands: a nationwide cohort study. BMC Pregnancy Childbirth, 15 (February) (2015), p. 42.
27) W. Christiaens, M.J. Nieuwenhuijze, R. de Vries. Trends in the medicalisation of childbirth in Flanders and the Netherlands. Midwifery, 29 (January (1)) (2013), pp. e1-e8.
28) Retrieved from https://zoek.officielebekendmakingen.nl/stcrt-2014-18656.html. [Accessed 31 August 2017].
29) Retrieved from https://med.stanford.edu/news/all-news/2009/09/lasting-impressions-gunshot-case-led-doctor-to-rethink-medical-training.html. [Accessed 1 May 2017].

7

When the hospital is no longer an option: A multiple case study of defining moments for women choosing home birth in high-risk pregnancies in the Netherlands.

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Abstract

Some women in a high-risk pregnancy go against medical advice and choose to birth at home with a "holistic" midwife. In this exploratory multiple case study, grounded theory and triangulation were employed to examine 10 cases.
The women, their partners, and (regular and holistic) health care professionals were interviewed in an attempt to determine whether there was a pattern to their experiences. Two propositions emerged. The dominant one was a trajectory of trauma, self-education, concern about paternalism, and conflict leading to a negative choice for holistic care. The rival proposition was a path of trust and positive choice for holistic care without conflict. We discuss these two propositions and make suggestions for professionals for building a trusting relationship using continuity of care, true shared decision making, and an alternative risk discourse to achieve the goal of making women perceive the hospital as safe again.

Introduction

In the Netherlands, and other high-income countries, some women who are considered to have a high-risk pregnancy go against medical advice and choose to birth at home. Home birth with a community midwife is common in the Netherlands and is an integral part of the maternity care system. However, this option is limited to women with low-risk pregnancies. High-risk pregnancies are supervised by obstetricians and these deliveries take place in the hospital. Lately, it has become apparent that not all Dutch women adhere to these recommendations. A small group of high-risk women opt for home birth with a community midwife in a "holistic" practice. This is usually a caseload midwife who accepts clients who choose to go against medical advice in their birth choices. The term "holistic" has been chosen to be consistent with the published literature on this subject. Another small group of women elect to forego any skilled attendance and attempt unassisted childbirth (UC) (Hollander, de Miranda et al., 2017).

In a recent scoping review, Holten and de Miranda (2016) found 15 studies on the motivations of women choosing to birth "outside the system", that is: UC, home birth in countries where home birth is not well integrated into the maternity care system, or a midwife-attended high-risk home birth. The countries included Australia, Canada, Finland, Sweden, the UK and the USA. The key conclusion of this review was that "concerns over consent, intervention and loss of the birthing experience might be driving women away from formal healthcare and that there is a lack of fit between the health needs of some pregnant women and the current system of maternity care in several high-income countries" (p.60). The authors argue that a dialogue on views regarding authoritative knowledge, risk, autonomy and responsibility must take place between pregnant women and their health care providers.

Feeley and Thomson (2016) in a study on freebirth (or UC) in the UK found that women who chose UC faced opposition and conflict from maternity providers. The authors found that conflict appeared to be an important factor in the choice to birth outside the system.

Maternity care providers are increasingly faced with pregnant women who refuse some or all proposed interventions. These decisions may appear to be at odds with what medical professionals deem best for the fetus. Hollander et al. (2016) in their article on the legal possibilities and ethical intricacies of refusing recommended maternity care found, in contrast to the general perception, that the conflict was not between the mother and child, but between doctor and patient. Communication could be the key to solving this problem.

Jenkinson et al.'s (2017) article on refusal of recommended maternity care in a hospital setting in Australia found that when women's birth intentions were perceived by midwives and obstetricians to be across their "line in the sand", a range of responses were seen and escalated from manipulation, judgment, and badgering to outright abuse.

To examine the phenomenon of negotiation during a birth consultation, 10 cases of Dutch women who elected home birth in a high-risk pregnancy were examined and the results are presented here. In this multiple case study, interviews were conducted with the women, their partners and their health care professionals (community midwives, holistic midwives and obstetricians). The interview data was analyzed to determine if a similar pattern of decision-making occurred in these cases, which had led to the decision to birth outside the system. If a pattern emerged, it would be important for health care professionals to be aware of it so as to improve their care.

The purpose of this study was to explore how the wish to birth outside the system was negotiated in consultations/clinical encounters between pregnant women and their health care professionals. Special attention was given to the defining moment in the decision to leave the regular maternity care system. Understanding what happens in this decision-making process can generate implications for improving maternity care with a goal to increase women's options and reduce negative choices.

Methodology

Design

The DESCARTE model (Carolan, Forbat, & Smith, 2016) was used in the design of this exploratory multiple case study. This case study research used a cross-case analysis of ten cases in which Dutch women with a high risk pregnancy chose to birth at home against medical advice. The context of this study was the phenomenon of women birthing outside the regular maternity care system in the Netherlands, and the focus was on the negotiation of care during conversations with health care professionals (midwives and obstetricians) wherein women with a high-risk pregnancy expressed their wishes.

Multiple case study design has been shown to be useful in exploring medical encounters (e.g. Barry, 2002; Ledderer, 2010). Whereas these studies combined interviews with (participant) observation, observation was not possible in this study since it was retrospective. Our interviews with the women who had chosen to birth outside the system took place months to years after their child's birth and their conversations with the health providers in question. Triangulation

of the interviews with these women, their partners and their health care professionals were instrumental to understanding the issue under study. In this deductive approach, cases were selected not only for their own intrinsic value, but also to provide insight into the phenomenon of deciding to have a home birth in a high-risk pregnancy (Rule & John, 2015). It was not the understanding of the particularities of each case (as in a naturalistic case study), but rather the identification of general patterns that was the goal of this study (Abma & Stake, 2014).

Theoretical Framework

Following Yin (2014), this multiple case (holistic) design used a theory-first approach with prior development of theoretical propositions to guide data collection and analysis. The following propositions based on a literature review were used as a theoretical framework. A discrepancy in the definition of authoritative knowledge complicates negotiations between women and health care professionals (Chadwick & Foster, 2014; Holten & de Miranda, 2016; Jordan, 1997; Tulloch & Lupton, 2003). Shared decision-making (SDM) and true autonomy within consultations between clients and health care professionals are problematic (Barry & Edgman-Levitan, 2012; Elwyn et al., 2012; Holten & de Miranda, 2016; Stiggelbout et al., 2012). Conflict arises around the negotiation of a birth plan (Chervenak & McCullough, 2017; DeBaets, 2017; Feeley & Thomson, 2016; Hollander et al., 2016). Conflict in negotiation can also lead to a search for more tailored care (Hollander, de Miranda et al., 2017; Schoot et al., 2005).

Defining moments in the decision to seek holistic (outside the system) care often lie in conflict or previous trauma (Feeley & Thomson, 2016; Hollander, de Miranda et al., 2017; Kotaska, 2017). As a rival proposition, the researchers explored if the choice to birth outside the system was a positive first choice rather than the result of conflict or previous trauma, as this was one of the themes in Holten and de Miranda's (2016) scoping review.

The researchers in this study used a feminist approach informed by Critical Theory, whereby the researchers had an idea of the root causes of the problem under investigation and sought to validate findings from previous research, and ultimately to advocate for change based on the analysis of the findings (Kincheloe, McLaren & Steinberg, 2011). A feminist approach was used to explain the focus on women's autonomy or lack thereof and the power differentials within the clinical encounter (Green & Thorogood, 2009).

Data collection

Our sampling approach was deductive. In all 10 cases, the women had a high-risk pregnancy and opted for home birth. Their partners and at least two professionals (community midwives, holistic midwives and/or obstetricians) involved in their care were also interviewed. Women were selected by several sampling methods: purposive (approaching certain nationally known advocates or famous "cases"), convenience (contacting potential participants who happened to be posting on an online maternity-care users forum during the time of recruitment) and snowball (referral of some participants by other participants or their midwives, who were informed about the study by the researchers). Women's partners, if available, were also asked for an interview, as were all their known caregivers provided the women gave permission for them to be contacted.

The interviews were semi-structured and took place from August 2014 through February 2016. All participants gave verbal informed consent. A topic list based on themes known from the literature (Holten & de Miranda, 2016) was used to guide the interviews with the women (Figure 1). Partners were encouraged to tell the story of their child's birth in their own words. Community midwives and obstetricians were asked about their recollection of the specific case of the woman in whose care they were involved, and about their attitude about women making birth choices against medical advice. The holistic midwives were involved in several cases and were interviewed about their general opinion regarding this phenomenon and the particulars of the way they practiced, instead of focusing on individual cases.

All interviews were conducted by one of the three authors, who are all female and have a professional interest in women's motivation to give birth outside medical guidelines. All have a medical background in midwifery/obstetrics and experience with in-depth interviews. One (Lianne Holten) had extensive previous experience with qualitative research as a medical anthropologist.

None of the women or their partners who were interviewed were known to the interviewers, either personally or professionally, prior to the interviews. However, some of the professionals (midwives and obstetricians) were known to the interviewers through their professional networks. Prior to the interviews, there had been email contact with all participants, asking for their participation and explaining the reasons, goals and methods of the study and the identity and background of the interviewer. For this study, permission was sought from and waived by the medical ethics committees of the Radboud University Medical Center Nijmegen and the Academic Medical Center in Amsterdam.

The interviews lasted between 30 and 120 minutes and were recorded by digital sound recorder. They were then transcribed verbatim either by a commercial company or by volunteer medical students. Quotes used in the text

were translated from Dutch into English by the second author. All sound files and transcripts were stored anonymously in a secured password-protected university digital storage system. Data are available by request; however, all data are sound files or plain text in Dutch and contain sensitive information. Therefore, they are not publicly accessible.

Figure 1 Topic list for the interviews with the women

Medical situation (high risk) in this and previous pregnancies
What did you want to do that was against medical advice?
Why?
What makes a good birth or a bad birth?
Relationship with maternity care provider (time, connection, needs)
Trust (in care provider, in yourself, in protocols, in evidence, in the system)
Preparation (people, sources)
Partner's position
Risk perception (yours, care provider's, how to weigh these)
Autonomy (informed consent, equality, control)
Fear (for what? Why?)
Needs (physical, emotional, social)
Defining moment (to deviate from protocol)
Search for alternative care(-r)

Data Analysis

The researchers in this study used a case-based (rather than variable-based) analysis. Qualitative data analysis software MAXQDA (VERBI Software GmbH, 2017) was used in the thematic analysis of the cases. The within-case analysis was informed by Charmaz's grounded theory (2007). The interviews with the participants were coded by all three authors and analyzed by the first two authors. The interview data generated themes that together with themes from the literature informed the theoretical propositions. The themes were then used as an analytical lens in the thematic analysis of the cases by the first author. The between-case analysis was modeled on Yin's (2014) pattern matching method. The researchers looked for replication and contradictions of all propositions. The purpose of this cross-case synthesis was to determine if the women followed a similar course, not to explain the particularities of negotiation within consultations between pregnant women and their health care providers. The researchers strove for rich narrative without risking confidentiality and therefore chose to only report on the cross-case analysis.

Trustworthiness/rigor

In the within-case analysis, triangulation of interview data from multiple sources (women, their partners and their health care professionals) on a single event served to increase the internal validity of this study (Morse, 2015). For the between-case analysis, pattern matching was used (Yin, 2014), whereby results were compared with an empirically predicted pattern (based on the literature) and rival propositions to strengthen internal validity. A member check was performed among holistic midwives in the form of a feedback focus group discussion. Analyzing multiple cases strengthens external validity. A case study protocol (propositions) was used as a standardized agenda for the researcher's line of inquiry, thereby heightening the between-case reliability.

Results

A total of 41 interviews with women (n=10), their partners (n=10, all male), community midwives (n=5, all female), holistic midwives (n=8, all female) and obstetricians (n=8, 2 female, 6 male) were conducted. In all 10 cases, the women had had a high-risk pregnancy. Three had attempted a VBAC (Vaginal Birth After Cesarean), three had had a breech birth, two had had twins, one had had a previous PPH (Post-Partum Hemorrhage) and one had had a high BMI (Body Mass Index) at the time of birth. All these women chose a home birth. In eight cases, they actually delivered at home, while in two cases the women eventually agreed to be transferred to the hospital due to a failure to progress. There were no cases of perinatal morbidity or mortality. Table 1 illustrates the characteristics of the women who were interviewed. Characteristics of the individual cases are not provided due to privacy concerns. Several cases had media coverage due to the women's involvement in malpractice suits and might be publicly recognizable. For the same reason, case numbers were removed from all citations.

Nine of the 10 cases followed a similar pattern (Figure 2) outlined by the six themes resulting from the data analysis. These women had experienced an event in their past (for example, a previous traumatic birth experience) that had caused an aversion to hospitals and medical staff. Following self-study, the women had acquired an alternative risk perception compared to the medical staff. They had begun to doubt the health care professionals' interpretation of the evidence for the proposed obstetric management. These women brought this aversion and differing risk perception into consultations with their health care professionals. In consultations with their community midwife or obstetrician, they often experienced a paternalistic decision-making model and a lack of autonomy. Inflexible use of a protocol by the health care professionals and/or the women's

inflexibility made compromise impossible and the hospital as a place of birth was no longer perceived as an option. These women then turned to holistic care, often as a last resort or second-best choice. In holistic care they found true SDM within a trusting relationship. In Figure 3 is an illustration of a rival proposition of a positive first choice for a home birth in a high-risk pregnancy, as demonstrated by one case.

Table 1 Characteristics of the women

Characteristics	N=10
Women with high Risk Pregnancy	
Risk factor	
VBAC	3
Breech (1 also post term)	3
Twins	2
Previous PPH	1
BMI > 35	1
Age at delivery (years)	
>25-30	1
>30-35	6
>35-40	3
Parity during relevant delivery	
1	3
2	3
3	3
4	1
Employed	
Yes	8
No	2
Highest education	
High School	1
Vocational training	2
College	2
University	5
Marital status at time of relevant delivery	
Married	6
Living together	4

Primary Proposition: A Negative Choice

Previous traumatic experience.

In all nine cases, the women felt that they were safer giving birth at home than in the hospital, and most had a strong aversion to birthing in a hospital. In two cases, the women had experienced previous hospital admissions as extremely stressful.

> *"[…] in a hospital I am very nervous, tense, uncomfortable, my blood pressure goes up, all things that I thought [I could prevent] with the undisturbed birth that I could have at home, which would therefore also prevent the postpartum hemorrhage and the shoulder dystocia, those are all things that I [feel that I] would seek out if you would make me go to a hospital. I so dreaded that." (woman, high BMI, home birth)*

In six cases, the women had had a negative experience during a previous birth. These were not related to a poor obstetrical outcome (there were no cases of previous perinatal deaths or major maternal or neonatal morbidity). The women explained that they had experienced a lack of autonomy during medical interventions during birth (e.g. an induction of labor, instrumental delivery or cesarean section) as traumatic.

> *"He says: 'I am not here for my own amusement; I am here to help you.' And he rams that vacuum pump in, literally. Like that! […] It has left me with vaginism. I never had that problem before." (woman, home VBAC*

In four cases, an experience during the current pregnancy was also perceived as traumatic. These situations involved a lack of autonomy as well.

> *"But before I knew it they were prodding my stomach to see if they could do an external cephalic version. That really made me close down. I felt so, […] like my sense of self-worth was compromised. That I thought: somebody is messing with my baby, without asking for permission, without any explanation. I thought: what is this? […] I would rather just go for a breech birth than have to go through this again… It really was a traumatic experience." (woman, home breech birth)*

Some health care professionals we interviewed were aware of the fact that many women who birth outside the system have had a previous traumatic experience in the hospital. They believed that this made caring for these women difficult, because of the extra time needed to ameliorate previous trauma, and that they were placed at a disadvantage by a pre-existing lack of trust.

"[…] many people who have been traumatized during a delivery […] well, that's where something went wrong in the past. And wrong enough that when I am confronted with someone like that, I don't have the time or the space to repair the damage, to make them feel differently about the impending delivery. And that is a shame." (OB/GYN, male, home VBAC)

Community midwives and obstetricians often understand that previous trauma can influence a woman's choices, but this does not necessarily mean that they want to attend a high-risk home birth.

"When I see some women come home traumatized after a hospital delivery, I completely understand that you don't want to go back the next time. But I do believe that talking it through could help solve matters. If it doesn't, then everyone has their own responsibility to give birth in another way. Just not with me present." (community midwife, female, home VBAC)

Weighing the evidence.

After having had a negative experience in regular care, and vowing not to lose their autonomy again, the women started gathering information. They used websites, internet fora, and medical journals to increase their knowledge of obstetrics and heighten their trust and confidence in their ability to birth naturally.

"You can go on PubMed. […] There are all sorts of social media where you can discuss things with lots of different people. So, I do think that women standing up for themselves more is increasing. What they actually want is to discuss things on a different level. [Women] expect communication to be based on solid scientific information. And I also think that there are more women who say: you know, I will just trust in myself and trust that this will go the way it is meant to go and I will just stay home." (woman, twin home birth)

Some health care professionals have noticed a shift to a more empowered clientele. They feel that there is a growing awareness among women that they have the right to refuse medical advice.

"She read a lot then, too. She was busy with all kinds of dissertations trying to weigh the risk for herself. She had also given me a lot of information, and for her, the decision was that she said: 'That is a risk I am willing to take, that I will experience a uterine rupture at home.'" (community midwife, female, home VBAC)

With their newly gained knowledge, these women critically appraised the relevant protocols and guidelines, and the statistics they were based on. Often, they decided that the risks did not apply to them or that they were willing to take their individual risk.

> *"The downside of evidence-based medicine is that you only know what you know. There has never been a study comparing breech birth at home versus at the hospital. So, the risks associated with a breech birth compared to a normal cephalic birth [in the hospital] can't be extrapolated to the fact that I gave birth at home. Of course, that is exactly what is being done. They are group statistics. You can't apply those to one individual. That bothers me. So, I think that the risk of complications [at home] is smaller than the literature shows. That is why I completely focused on: all will be well." (woman, home breech birth)*

Several health care professionals were also critical of the evidence many protocols and guidelines they were expected to adhere to were based on:

> *"But, if you look at which part of the guidelines is actually really evidence-based, of course, that is only one page. So, we are all saying things like…expert opinions and I don't know what else, and so that changes over time. So, I find that somewhat difficult, if you go around spouting that as the truth. And our proposition at our national meeting was, let's start by being clear about what is really evidence-based, where the gaps in our knowledge are, and then we can investigate those and supplement our knowledge. I could work much better like that. So, those are my thoughts about our guidelines. I am not so…not such a fan of the guidelines." (OB/GYN, female, high BMI, home birth)*

After weighing their risks, women decided that the interventions they feared would take place in the hospital posed more of a risk to them and their baby than a home birth did.

> *"I felt that those risks were because of the interventions. At some point I had the notion that if I made sure I had a good, physiological process, I would not run that risk at all. That I was actually keeping that risk at bay." (woman, previous PPH, home birth)*

Some women also felt that the risks they took having a home birth in a high-risk pregnancy were outweighed by the possible negative effects of (routine) interventions. As one OB/GYN concurred:

"Of course, it is quite difficult to…many of the things we do routinely, to indicate which of those are actually useful. […] And then, some people say: "Well that is such a small risk." That doesn't justify the intervention, for me." (OB/GYN, male, home breech birth and home VBAC)

The women stepped into the consultation with their health care professional with this (alternative) risk perception and aversion to the hospital.

Paternalistic decision-making and a perceived lack of autonomy (again).
Most health care professionals were of the opinion that the style of counseling pregnant women has changed over time and that this is a good development.

"What I am realizing more and more, is that we are slowly moving from 'informed-consent' to 'shared decision' to 'informed choice'. In which the patient makes an informed choice, and that you... that I find myself respecting that more and more." (OB/GYN, male, home breech birth and home VBAC)

However, in 8/10 cases, the women felt that there had been no SDM during health care provider consultations in which they discussed their wishes for giving birth. They experienced a paternalistic style of counseling and a lack of autonomy.

"I was just not heard at all. […] there has actually never been anyone who asked me: why don't you want to give birth in the hospital?" (woman, high BMI, home birth).

The women felt there was no room for their wishes and that they had limited choice, as one woman's partner articulated:

"I do expect [of the midwife], that if you are told 'no', that you will be offered something else, or… some alternative or in any case something to discuss, let there at least be some form of discussion, we have had a few instances where no discussion was possible and I found that very, uhm, what shall I say…disappointing." (partner, male, high BMI, home birth)

Yet most health care professionals were convinced that they had counseled the woman adequately and did not understand where it had all gone wrong, as the following quote by an obstetrician counseling in the case of a breech presentation illustrates:

> *"She was referred for a breech position, after which we discussed her wishes: what she would want and what she didn't want. I explained the possibilities at length and told her that as far as I was concerned, we could accept her for a vaginal breech delivery. […] Then I explained [to her] how this works, where, in case of an intent to deliver vaginally, there are conditions, in terms of [the following]: is there enough progress during dilation, is the estimated fetal weight not too high. And the progress during the second stage also needs to be sufficient, and therefore, there can always come a time during the delivery that we say: 'well, now there is a reason to make a different choice'. Well, that in itself was ok. It was a normal conversation. I don't remember anything unusual about it. It was just accepted….as it is usually accepted by most people. I made a follow-up appointment and never saw her again." (OB/GYN, male, home breech birth)*

In this case, the obstetrician was convinced that the consultation had gone well. The woman however, experienced a complete lack of autonomy, which led her to abandon plans for a hospital birth in favor of a home birth. This is how the woman experienced the same encounter:

> *"He [OB/GYN] said: 'Ok, a vaginal breech birth. There are a number of conditions' […] … he ended that story with: 'But anyway, I have the final say during the delivery.' And then I thought: wait a minute, am I not the one giving birth? I was given no further explanations. So, we just went home. It was such an unsatisfactory feeling […] I have never felt like I was a … not so much equal partner but as a serious participant in this conversation. While I am the one carrying this child." (woman, home breech birth)*

There were two cases in which women were satisfied with how they had been counseled in the hospital. In one case, the woman who was pregnant with twins and desired a home birth, had a consultation in a clinic that specializes in consultations with women who want to birth outside the system. The other case was a woman who wanted a VBAC at home. She was counseled by an obstetrician who also involved the community midwife in SDM.

Inflexibility: conflict in negotiation.

In all cases but one, there had been some form of conflict during negotiation of the women's birth plan. Women encountered inflexibility from community midwives and obstetricians with regard to deviating from guidelines or protocol. In three cases, health care professionals threatened to call child protective services, and two actually did. In two other cases, the obstetricians lodged a formal complaint against holistic midwives for attending high-risk births at home. All this caused a great deal of stress for the women involved.

> *"[…] at first I sent my birth plan and then we talked again, and that was when he let me know that they were not willing to make any concessions and that continuous [fetal] monitoring was an absolute requirement. […] Then we said: ok, well then, we will do things differently. And that is when the telephone conversation became distinctly unpleasant. That he said: 'Yes, well, that is not allowed, and a midwife who does this is acting against the law. Your child has rights too.' That was unpleasant. […] One and a half hours later he phoned and said: 'I am going to report you to child protective services, because you want to have a home birth.' […] As far as we were concerned, that definitely closed the door to the hospital. It was quite intense too, because I was thirty-nine weeks at the time. I found that very threatening." (woman, home VBAC)*

In some instances, the women had been in contact with more than one obstetrician from the same clinic and had encountered two very distinct viewpoints. This did not increase their confidence that the clinic would respect their wishes during their labor. In one case, an obstetrician expressed his negative views on women who chose home birth in a high-risk pregnancy in a telephone conversation with a community midwife, as she explained:

> *"[the obstetrician said] 'Someone who opted for a home birth was just a borderliner. […] If that lady really didn't want that [the hospital], then something was not right. Then she should be reported to child protective services.' […] That was the actual advice from the hospital. […] No, we did not report her .[…] I do not feel that she made a decision based on not wanting to care for her child properly." (community midwife, female, home VBAC)*

However, another obstetrician from the same department, who saw the woman later on, had other ideas, and was very set against involving child protection services.

> *"And in this situation, I am dealing with two, in my mind, very realistic people with an obvious trauma which has not been dealt with. I do not labor under the illusion that child protective services deals in trauma therapy. I also estimate chances are good that running to child protective services will double the trauma, so for me that was not a realistic option." (OB/GYN, male, home VBAC)*

In consultations, health care professionals often felt that they had done their best to reach a compromise, but that the women themselves were too inflexible in their wishes.

> *"I was really amazed that she thought we were being too 'medical', while actually, all other things besides a home birth, that we should have done, according to regional protocols, we didn't do. We decided not to do those. We thought: oh well, if she doesn't want those, that's fine." (community midwife, female, previous PPH, home birth)*

At the same time, this community midwife's client had experienced their negotiation of her birth plan as inflexible.

> *"They said, yes, you have to give birth in the hospital, you can't have a home birth any more. And well, I had just been working on taking charge of my autonomy, so the sentence "you can't have a home birth any more", that was, that was just very unpleasant for me. I felt that was an unpleasant conversation. And also, for instance, that they said, like, 'yes, because you lost so much blood we want to put in an IV and you will get oxytocin right away.' […] It wasn't that I didn't want that, but I didn't want it to happen just because they said so." (woman, previous PPH, home birth)*

In this particular case, the community midwife was aware of her client's opinion about the consultation. However, often women avoided conflict by leaving regular care without giving their health care professionals an explanation.
The partners' role in the negotiation of the birth plan seems limited. In all cases, partners left it up to the woman to inform them of her choices and they respected her choice.

> *"I just supported her all the way. I let her do the research because I felt that she, it had to be right for her, and, well, I could see that after a while it calmed her down, and it is…we did talk about it a lot, you know, she kept me informed the whole time of what she had found this time. […] It was her that convinced me." (partner, male, previous PPH, home birth)*

In one case, the partner was not aware that his wife was considered to have a high risk pregnancy (twins):

> *"I also wonder if this is actually a high-risk pregnancy. Is this always automatically high-risk? […] Ok. I did not experience it as such. […] Also, haven't really given it much thought. I did consider it as higher risk than a singleton pregnancy, but… didn't really give it much thought." (partner, male, twin home birth)*

In 9/10 cases, conflict during the negotiation of a birth plan was a reason for the women to search for care outside the system.

Holistic care: a last resort/second best choice.

In all 10 cases, the women started care with a midwife and decided during their pregnancy to go against medical advice and protocol by choosing a home delivery. The women found that the wishes they had for their birth could only be met by a holistic midwife, since the community midwives and/ or obstetricians were unable or unwilling to help them. Holistic midwives were more accommodating to the women's wishes. These midwives had other criteria for agreeing to attend a home birth compared to hospital guidelines or protocols.

> *"Yes. I go along with every wish. If I feel like people are actually taking responsibility for it themselves. I have to feel like they have thought it through sufficiently. That they are coming from a position of strength and not from fear. For instance, not from fear of ending up in a hospital, but from a conviction or a trust in something in themselves, or whatever. I have to feel like they can carry themselves. If not, I won't do it." (holistic midwife, female, home VBAC)*

Some community midwives and obstetricians actually worked together with holistic midwives and realize that they address a need for personalized care.

> *"I also feel that we are learning a lot from this. I think that […] patients are having trouble recognizing themselves in hospital care as it is sometimes offered. Too impersonal, not involved enough. That they really miss that [the personal involvement] and opt for a caseload midwife to monitor their pregnancy and ... I actually feel that you can make tremendous use of that model and still have a good basic outcome for these women." (OB/GYN, male, home breech birth and home VBAC)*

In most cases, the women found their holistic midwives through the Facebook community *De Geboortebeweging* ("the Birth Movement") on the internet. In two cases, women actually started their pregnancy in holistic care, but in most cases, the women had switched to holistic care late in their pregnancy (sometimes just before the due date) when all other options had been exhausted.

In one case, the woman wanted a VBAC at the hospital with her own midwife. The consultation at the hospital ended in conflict and the hospital refused to admit her. The adjoining primary care birthing center also refused her because they were afraid of a bad outcome.

> *"Then I thought: 'Well, then we will go do it at home, to make a statement. If she is not welcome in the hospital nor in the [birthing center], then she will have to stay home. And we can't let her down.'" (community midwife, female, home VBAC).*

Since not all of this community midwife's colleagues agreed to assist during a home VBAC, eventually this woman had to find a holistic midwife.

In another case, a woman, pregnant with twins wanted to birth in the hospital with her holistic midwife. The hospital refused. The conflict between the woman and the obstetrician escalated so that she decided to birth at home without telling the obstetrician. The birth stagnated, yet the woman waited more than 24 hours before she went to the hospital.

> *"Well ... see … in hindsight, I have been thinking that it shouldn't have come to this. Where your relationship [with the hospital] is so disturbed that even when the delivery is not going at all as it should, you still don't want to go to the hospital." (partner, male, twin home birth).*

In 6/10 cases it was not the woman's first choice to birth at home. In four of these cases, the women were prepared to deliver in the hospital with an obstetrician if some of her requests had been honored. In the other two cases, the women wanted to deliver in the hospital with their holistic midwife, but this was not allowed. Thus, for these women delivering in the hospital was no longer an option and they saw home birth as their last and only choice.

Defining moment: the hospital is no longer an option.

In nine cases, the defining moment in the choice to birth outside the system lay in the fact that for these women the hospital felt like it was no longer an option. After a conflict with their obstetrician, some women and their partners felt that the risks of delivering in the hospital were greater than the risks of a home birth.

> *"We felt like (my wife) would be on the operating table in no time at all for a cesarean section. […] That is how we interpreted the conversation with [obstetrician]. He literally said: 'I prefer to do only cesareans, because then I can plan them so I don't have to get out of bed at night.' We just didn't feel safe in the hospital, so that is why we delivered at home. […] If all [the consultation] had gone well, then I think we would have just delivered in the hospital. And then we would have probably been just as happy." (partner, male, home breech birth)*

For some women, the defining moment was when they felt they had no autonomous choice in the hospital.

> *"Then [we had] the desire to not immediately implement that active management of the placenta. When it was actually being said that there is no question, that that is possible. Then I thought, well yes, but then this is not the right place for me. Then, I*

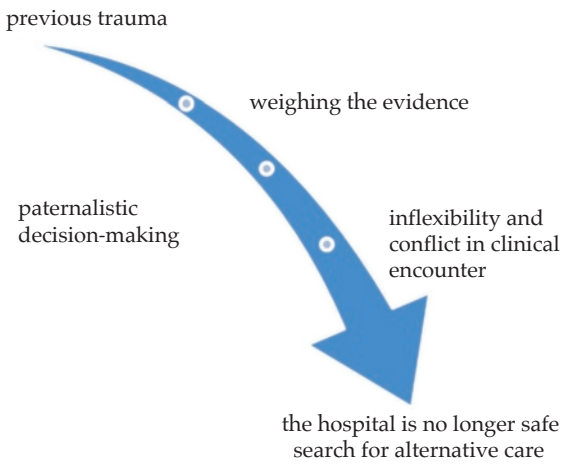
do not feel heard. […] I know exactly at which appointment that happened, and I said that evening that this is not going to work out this way." (woman, twin home birth)

Women and their partners felt that they could not choose which interventions would or would not be done, such as active management of labor or continuous fetal monitoring. Nor could they choose their mode of birth, for example a breech on all fours or a VBAC in a birthing pool.

"Especially certain wishes that she [pregnant woman] had that could not be met by the hospital. From her third [delivery] she knew that she liked giving birth in the bath. And that was impossible. But, what also factored in, was that she did not have a good feeling at all… about the hospital. Because they just dictated to her what she would do: 'You will do this and that and that and now we will do this and that.' Yes… that is also a strange way of caring for a pregnancy." (partner, male, twin home birth)

At a certain moment, often after a conflict with an obstetrician, the women felt that the hospital had become unsafe, or even dangerous and/or that the hospital was a place where true autonomy was not possible.

Figure 2 Proposed mechanism of traumatic experience, conflict and negative choice



Rival Proposition: Positive Choice

Negative case.

One case followed an alternative pattern (Figure 3). This case involved a nulliparous woman with a breech presentation who had not had a previous traumatic experience and did not have any conflict in the negotiation of her birth plan. She had started prenatal care with a holistic midwife, apparently by coincidence, and did not consult an obstetrician during her pregnancy. She did not have an aversion to the hospital.

> *"There is actually nothing wrong at all with a protocol and with giving birth in a hospital or under medical supervision, except my truth is […], that it has to feel good and right, from within myself. Because I personally just believe that every person, but also a baby, being a soul, makes certain choices, and that is a factor for me, and I really believe that a baby can actually make a conscious decision to be born in a hospital or not […] If I had felt that a planned cesarean section was meant to be, then I would certainly have been open to that." (woman, home breech birth)*

This woman's membership in an internet community and her trust in birth as a physiological process played a defining role in her choice to deliver at home with her holistic midwife.

> *"It is always a feeling of course, but indeed, also stories that I [saw] on the internet. YouTube is full of home breech birth movies." (woman, home breech birth).*

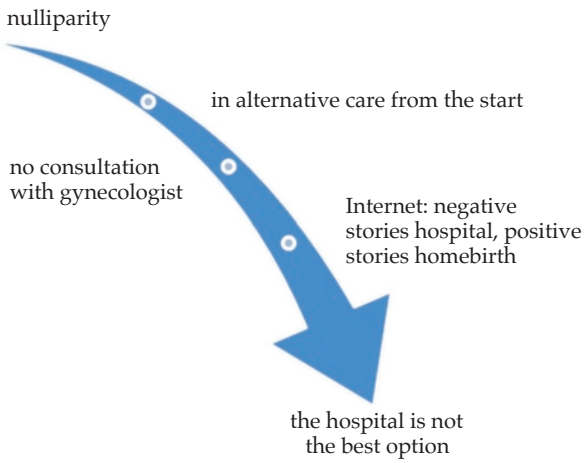
Some community midwives and obstetricians believe that certain internet fora actually create distrust and fear of the regular system and put women on the path of home birth in a high-risk pregnancy.

> *"What I find difficult about that, is that there are actually certain movements, for instance the 'Birth Movement' in the Netherlands, which, to my mind, create some sort of bias. […] Who create a certain situation of distrust, which is not right either. So, I find that to be a shame. […] where it is stated beforehand, that the doctors won't listen. That there will be too many medical interventions and that unnecessary things will be done, and that opinion makes people afraid. So, in part it [birthing outside the system] is based on trauma and part it is based on information which I feel is not always accurate." (OB/GYN, male, twin home birth)*

A holistic midwife explained that, according to her, there are two groups of women who choose to birth outside the system—those that have fear and those that trust:

"There is a part, I think 75 percent, who come out of fear. They come [to me] because they are afraid of the hospital, that someone will think something of them, and will want them to do something they don't want to do. To be taken over. There is a lot of fear there. Often, there is sexual abuse behind it. And then there is a smaller percentage, that is I think 25 percent, of people who come because it is just a better fit. They have no fear of hospitals, they don't fear…decisions that may need to be made. And they just have confidence in things being right. So, there is a small group of trust and a larger group of fear." (holistic midwife, female, high BMI, home birth)

Figure 3 Rival proposition of positive choice



In this negative case, there was no conflict in the negotiation of the birth plan because there was no consultation with a regular community midwife or obstetrician. Even though there was no aversion to the hospital, the internet had an important part in the representation of the hospital as being not the best option for a breech birth.

Discussion

The results of this multiple case study demonstrate that there is a discrepancy in the definition of authoritative knowledge that often makes negotiation difficult. Women may feel that their true autonomy during consultations with health care

professionals is threatened and conflicts arising during the negotiation of a birth plan may lead them to search for more tailored care.

Whereas one woman's story followed an alternative pattern that supported the rival proposition of a positive choice, the other nine women followed the primary proposition of a negative mechanism. This confirmed the theory of a traumatic experience and conflict resulting in a negative motivation to choose a holistic birth.

What this multiple case study adds to existing knowledge:

1. The defining moments in the decision to seek holistic (outside the system) care usually lie in conflict during consultations. These conflicts are often triggered by a birth plan based on a previous traumatic experience. Behind motivations to birth at home with a high-risk pregnancy lie a negative experience with the regular maternity care system. This includes negative stories about the system on the internet.
2. There is often a discrepancy in how health care professionals and women perceive their clinical encounters.

Traumatic Experiences and Conflict

In all cases, the women's negative experiences or trauma involved a perceived lack of autonomy, during either a previous birth or their current pregnancy. This finding is similar to Byrne, Egan, Mac Neela, and Sarma (2017), who described health care professionals ignoring and discounting a woman's identity and individuality, and a "loss of self" throughout the process of childbirth that led to the perception of birth as traumatic. Similarly, Henriksen, Grimsrud, Schei, and Lukasse (2017) found that "not being seen or heard" and an "experience of pain and loss of control" led to the perception of birth as traumatic. In a recent Dutch study of 2192 women, Hollander, Hastenberg et al. (2017) found that women attribute their traumatic childbirth experience primarily to a lack and/or loss of control, issues of communication, and the lack of practical and/or emotional support. These women believed that in many cases, their trauma could have been reduced or prevented by better communication and support by their caregiver.

Based on the results of this multiple case study, it seems likely that previous trauma may make it very difficult for women and professionals to have a consultation without conflict, because women no longer experience trust in the health care professional. They are so afraid to lose their autonomy again that they (and therefore their birth plans) become inflexible. Health care professionals, on the other hand, find it difficult that these women question their biomedical risk definitions by wanting to deviate from guidelines. They believe that women are putting the safety of their child at risk in order to have a better birth

experience. Such a consultation seems doomed to be difficult. DeBaets (2017) has also reported that birth plans can often lead to frustration and antagonism between patient and providers.

In the matter of conflict over a proposed birth plan, Chervenak and McCullough (2017) state that an "unlimited-rights model of obstetric ethics is an unacceptable over-reaction to physician paternalism and therefore a threat to professionalism in obstetrics" (p. 1144). They posit that SDM (and an emphasis on client autonomy) is not possible or even desirable in many clinical circumstances. Chervenak and McCullough advocate that what they call the unlimited-rights model should be replaced with a "professional responsibility model", wherein there is room for evidence-based, directive SDM (p. 1146). Some health care professionals suggest that attending a woman who chooses to accept more risk than they deem necessary is enabling her choice. They believe that by refusing to assist women who insist on birthing outside the system, they will force the women to change their minds. However, Kotaska (2017) posits that in actuality, many (if not most) women may choose to forego professional assistance instead. Thus, both the women and their babies end up in a higher risk situation than they initially set out to be. This was also a finding in this multiple case study.

Negotiating the Birth Plan and the Role of the Professional

Although community midwives and obstetricians are often of the opinion that they counsel women adequately, the women in this study felt otherwise. The women interviewed in this study experienced a lack of autonomy and subsequently believed they had no true SDM. This finding is similar to Jenkinson et al. (2017), who demonstrated that clinicians claimed to respect women's autonomy, but still invoked a "line in the sand" which they were unwilling to cross. The professionals believed that this gave reasonable women enough room for their own input for the birth plan. Although caregivers in Jenkinson et al.'s study tended to deny or minimize the frequency of coercion, they simultaneously described coercive practices, which can also be seen in the current multiple case study.

Shared Decision-making

Many health care professionals feel they use SDM in most, if not all, of their consultations. This is also true for the health care professionals in this study. Yet, researchers have identified a perception-reality gap. Despite obvious benefits, SDM is still not routine in clinical practice. Stiggelbout et al. (2012) posit that the use of guidelines may make the implementation of SDM difficult, especially if patient preferences are at odds with guideline recommendations and/or with health care professional preferences. When professionals are using guidelines,

client preferences are generally not elicited or are overruled and options are not given. It appears clinicians find it very difficult to discuss options they do not personally support, or if they have a very clear (guideline-inspired) preferences. Several community midwives and obstetricians in Stiggelbout et al.'s study went immediately to risk talk and explaining the harm and benefit of the situation, thereby giving women no option but to follow protocol.

According to Elwyn et al. (2012) there are three important steps in SDM: choice talk, option talk and decision talk. The health care professional should support deliberation throughout the process. Choice talk refers to the step of making sure that patients know that reasonable options are available. Option talk refers to providing more detailed information about options and decision talk refers to supporting the work of considering preferences and deciding what is best. (Elwyn et al., 2012, p. 1363).

Health care professionals could improve their SDM skills using choice talk, option talk and decision talk as an alternative to risk talk. However, the results of this multiple case study show that better SDM skills by themselves are not enough. Women with high-risk pregnancies who choose home birth are often using a discourse very different from the clinicians' biomedical risk definitions, which makes the clinicians uncomfortable. It appears that pure SDM, as described by Elwyn et al., only works optimally when all available options are acceptable to the professional, at least to some extent.

Discussing Risk

While in general risk is assumed to be negative and risk avoidance is regarded as normal, Tulloch and Lupton (2003) have shown that lay people can see risk knowledge as "situated rationalities", and these compete with expert risk knowledge (p. 9). For example, women with high-risk pregnancies who opted for home birth in this study rejected the biomedical definition of their birthing bodies as inherently risky, and instead perceived the process of giving birth in medicalized settings as risky. Thereby, the women provided an alternative construct of the birthing body as a site of knowledge and an active capacity. This articulation of birthing bodies as "knowing bodies" threatens biomedical conceptualization of the birthing body solely as a source of risk and potential dysfunction.

Similar to findings in Chadwick and Foster's (2014) study on women who gave birth at home in South Africa, the women in this multiple case study were classified by biomedical discourse as bodies at risk for complications. The women, however, perceived themselves as vulnerable bodies at risk of being objectified, losing autonomy and experiencing trauma. For the women in this study, their choice for a home birth in a high-risk pregnancy functioned as a strategy for reducing potential vulnerabilities and risk in their birth process.

This may help to explain the importance of "situated rationalities" or lay risk knowledge (such as intuition) over expert knowledge in everyday lived experiences and why this alternative discourse is uncomfortable for health care professionals. Given the above, it is no wonder that discussions about risk during a consultation between clients and professionals can be fraught with misunderstanding. Edwards, Elwyn, and Mulley (2002) speak of suboptimal risk communication, and advocate that communicating risks should be a two-way process, in which both professionals and patients exchange information and discuss how they feel about those risks. This requires professionals to understand the various risk concepts that patients may have. Edwards et al. (2002) state that care providers need to assist patients in making choices by providing statistical data as absolute rather than relative risks to avoid manipulative "framing" of data with the goal of coaxing the patient towards the "desired" choice.

The Professional as Coach/Partner

Unfortunately, SDM skills and an understanding of lay risk knowledge are not enough. According to Barry and Edgman-Levitan (2012), to engage patients in decision making, health care professionals need to let go of their role as the single authority and train to become more effective coaches or partners. They must learn how to ask, "What matters to you?" as well as "What is the matter?". Porter, Crozier, Sinclair, and Kernohan (2007) posit that some health care professionals may be uncomfortable with the new rebalancing of power relationships between professionals and their lay clients. Schoot et al. (2005) in their study on interactions between patients and their caregivers aimed at tailoring care to the client demand, found that recognition of client values underlying their demand (such as uniqueness and autonomy) and recognition of values underlying the care relationship (such as equality and partnership) were the basis for tailored care. Klaver, van Elst, and Baart (2014) state that the process of care starts with the recognition of a need, which cannot be done without attentiveness to the client's perspective. It then follows that good care is about recognition—women want to be seen. This means that attentiveness and care are indelibly connected, since good care cannot exist without attentiveness. As demonstrated in this multiple case study, many obstetricians and community midwives take a somewhat opposing view of their professional role.

A Trusting Relationship

Jenkinson et al. (2017) state that relationships are key in all consultations between professionals and clients. In their study on pregnant women, clinicians emphasized the importance of building trusting relationships with women, but at the same time acknowledged that this was challenging in a busy public hospital. This

finding was confirmed by O'Brien, Butler, and Casey (2017), who stated that women's understandings revealed that informed choice was not only defined by but also dependent on the quality of women's relationships with their caregivers and the caregivers' ability to engage in SDM with their clients. In that study, informed choice was experienced as a relational construct. The authors found that the support provided by maternity care professionals to women in contemporary maternity care must reflect this. Dahlberg and Aune (2013) and Todd, Ampt, and Roberts (2017), in their respective studies, also defined relational continuity as a key concept in the context of a positive birth experience. The current multiple case study also demonstrates that whereas a good relationship (for instance with a holistic midwife) can prevent trauma, while distrust of the professional due to a previous traumatic experience can make the relationship difficult. As Reed, Sharman, and Inglis (2017) posit, it is necessary to address interpersonal aspects of birth trauma. Women who experience a lack of continuity in their care find it difficult to establish a trusting relationship with their caregivers, which makes negotiating a birth plan increasingly troublesome.

Implications for Practice

Prevention of conflict and negative choices starts with the original traumatic experience. In order to prevent a negative birth experience, based on perceived loss of autonomy and lack of support, professionals should invest in the continuity of care and a respectful relationship with their clients based on equality, partnership and true SDM. This requires introspection and awareness on the part of the professional regarding their own concepts and perception of risk. Once there is trauma and distrust, any consultation or negotiation between client and professional will almost automatically be difficult and lead to conflict. This may well result in the hospital no longer being perceived as a birthing option, and lead women to turn to holistic midwives and a home birth in a high-risk pregnancy. If we as professionals want fewer women to make this negative choice, then hospitals must be perceived as safe again. This can only be accomplished by establishing a reputation of respect, trustworthiness and equality between women and professionals. In cases of continuing disagreement about a birth plan, second-best care must be explored to prevent choices for even higher risk options.

Further study is needed to understand why some women with high-risk pregnancies, who may have suffered an equivalent trauma in the past, have chosen to stay in the hospital system. It is important to determine which health care professional approaches have led to trust being regained. This knowledge could provide health care professionals with the tools they need to prevent the trajectory of events described in this study.

Strengths and Limitations

A strength of the theory-first approach using propositions is that it generated a strong research design and clear focus for data analysis. However, a limitation of this approach is that some unanticipated findings across the cases may have gone unnoticed. The instrumentality of the cases in testing the theoretical propositions does not allow for a study of the intrinsic interest of the individual cases (Rule & John, 2015).

Another strength of this study lies in the fact that 41 interviews with women, partners and caregivers provided a wealth of thick description, and highlighted multiple viewpoints relating to 10 cases of women with a high-risk pregnancy who elected to have a home birth. This allowed for triangulation between the experiences of all parties present at the same event, and demonstrated how several people had very distinct recollections of the same conversation. The fact that there were 10 separate cases to analyze made it possible to reliably establish a pattern in the trajectory of the vast majority of these cases. This enabled us to make several pertinent recommendations for health care professionals and help guide their future negotiations with women in this situation. Hopefully, this will prevent more women from resorting to negative choices that entail more medical risk than they initially set out to take.

A limitation of this study is recall bias. Some obstetricians could not initially remember the specific case they were questioned about. In those instances, they made use of their notes in the electronic patient file, which usually triggered their memory and helped them recall the case in more vivid detail.

As a member check, a focus group discussion was held with six holistic midwives in which the results of this multiple case study were shared. The participants recognized and agreed with the patterns described above, which heightened the validity of this study. However, the midwives remarked that the majority of our sample were extreme (high-risk) cases and that the more extreme the case, the more likely that the woman's choice was based on a negative experience with the current system of maternity care. The midwives found our emphasis on trauma was a bit heavy-handed. They believed it was possible that we could have found more women with a high-risk pregnancy making a positive choice for a home birth had we interviewed more women with relatively minor increases in risk. On the other hand, the fact that we had so many extreme cases in our sample can also be considered as a strength, because in these cases, caregivers are most worried about the outcome for mother and child and so these cases are the most important to understand.

Conclusion

In this multiple case study, we examined the negotiations between health care professionals, women and their partners in 10 cases of women with a high-risk pregnancy who had gone outside guidelines/protocol and had a home birth. The vast majority (nine) of these cases followed a similar trajectory, wherein a previous traumatic experience and a paternalistic decision-making by the health care professional led the woman to weigh the evidence for themselves and decide on an alternative birth plan. Negotiating this birth plan with their health care provider led to conflict as both parties experienced a lack of flexibility from the other side. This in turn resulted in a defining moment when the women decided that the hospital was no longer an option.

One case followed another pattern, in which trauma did not play a role and there was no conflict. This woman with a high-risk pregnancy decided on a home birth as a positive choice based on trust and confidence.

It appears that the original proposition is the most common one. Therefore, we recommend that health care professionals invest in preventing the original trauma, become more aware of their own concepts of risk perception, practice true SDM and strive for continuity of care in an equal, respectful and trusting relationship, and thereby limit the risk of women making negative choices.

References

Abma, T., & Stake, R. (2014). Science of the particular: An advocacy of naturalistic case study in health research. *Qualitative Health Research*, 24(8), 1150–1161. doi: 10.1177/1049732314543196

Barry, C. (2002). Multiple realities in a study of medical consultations. *Qualitative Health Research*, 12(8), 1093-1111. doi: 10.1177/104973202236577

Barry, M., & Edgman-Levitan, S. (2012). Shared decision making-pinnacle of patient-centered care. *New England Journal of Medicine*, 366(9), 780-781. doi:10.1056/NEJMp1109283

Byrne, V., Egan, J., Mac Neela, P., & Sarma, K. (2017). What about me? The loss of self through the experience of traumatic childbirth. *Midwifery*, 51, 1-11. doi:10.1016/j.midw.2017.04.017

Carolan, C., Forbat, L., & Smith, A. (2016). Developing the DESCARTE model: The design of case study research in health care. *Qualitative Health Research*, 26(5), 626-639. doi:10.1177/1049732315602488

Chadwick, R., & Foster, D. (2014). Negotiating risky bodies: childbirth and constructions of risk. *Health, Risk & Society*, 16(1), 68-83.

Charmaz, K. (2007). *Constructing grounded theory. A practical guide through qualitative analysis* (2nd ed.). London: Sage.

Chervenak, F., & McCullough, L. (2017). The unlimited-rights model of obstetric ethics threatens professionalism. *British Journal of Obstetrics and Gynecology*, 124(8), 1144-1147. doi:10.1111/1471-0528.14495

Dahlberg, U., & Aune, I. (2013). The woman's birth experience-the effect of interpersonal relationships and continuity of care. *Midwifery*, 29(4), 407-415. doi:10.1016/j.midw.2012.09.006

DeBaets, A. (2017). From birth plan to birth partnership: enhancing communication in childbirth. *American Journal of Obstetrics and Gynecology*, 216(1), 31 e31-31 e34. doi:10.1016/j.ajog.2016.09.087

Edwards, A., Elwyn, G., & Mulley, A. (2002). Explaining risks: turning numerical data into meaningful pictures. *British Medical Journal*, 324(7341), 827-830.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., . . . Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361-1367. doi:10.1007/s11606-012-2077-6

Feeley, C., & Thomson, G. (2016). Tensions and conflicts in 'choice': Womens' experiences of freebirthing in the UK. *Midwifery*, 41, 16-21. doi:10.1016/j.midw.2016.07.014

Green, J., & Thorogood, N. (2009). Qualitative Methods for Health Research. London: Sage.

Henriksen, L., Grimsrud, E., Schei, B., & Lukasse, M. (2017). Factors related to a negative birth experience - A mixed methods study. *Midwifery*, 51, 33-39. doi:10.1016/j.midw.2017.05.004

Hollander, M., van Dillen, J., Lagro-Janssen, T., van Leeuwen, E., Duijst, W., & Vandenbussche, F. (2016) Women refusing standard obstetric care: Maternal fetal conflict or doctor patient conflict? *Journal of Pregnancy and Child Health* 3:2

Hollander, M., van Hastenberg, E., van Dillen, J., van Pampus, M., de Miranda, E., & Stramrood, C. (2017) Preventing traumatic childbirth experiences: 2192 women's perceptions and views. *Archive of Women's Mental Health*, 20:515–523.

Hollander, M., de Miranda, E., van Dillen, J., de Graaf, I., Vandenbussche, F., & Holten, L. (2017) Women's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis. *BMC Pregnancy and Childbirth*, 17:423 doi: 10.1186/s12884-017-1621-0

Holten L., & de Miranda E. (2016) Women□s motivations for having unassisted childbirth or high-risk home birth: An exploration of the literature on 'birthing outside the system'. *Midwifery*, 38:55–62

Jenkinson, B., Kruske, S., & Kildea, S. (2017). The experiences of women, midwives and obstetricians when women decline recommended maternity care: A feminist thematic analysis. *Midwifery*, 52, 1-10. doi:10.1016/j.midw.2017.05.006

Jordan, B. (1997). Authoritative Knowledge and Its Construction. In R. E. Davis-Floyd & C. F. Sargent (Eds.), *Childbirth and authoritative knowledge: Cross-cultural perspectives*. (pp. 55-79). Berkeley, CA: University of California Press.

Kincheloe, J., McLaren, P., & Steinberg, S. (2011) Critical Pedagogy and Qualitative Research; Moving to the Bricolage. In: N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research*. (pp. 163-173) London: Sage.

Klaver, K., van Elst, E., & Baart, A. (2014). Demarcation of the ethics of care as a discipline: discussion article. *Nursing Ethics*, 21(7), 755-765. doi:10.1177/0969733013500162

Kotaska, A. (2017). Informed consent and refusal in obstetrics: A practical ethical guide. *Birth*, 44(3), 195-199. doi:10.1111/birt.12281

Ledderer, L. (2011). Understanding change in medical practice: The role of shared meaning in preventive treatment. *Qualitative Health Research*, 21(1), 27–40. doi: 10.1177/1049732310377451

Morse, J. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25(9), 1212–1222. doi: 10.1177/1049732315588501

O'Brien, D., Butler, M., & Casey, M. (2017). A participatory action research study exploring women's understandings of the concept of informed choice during pregnancy and childbirth in Ireland. *Midwifery*, 46, 1-7. doi:10.1016/j.midw.2017.01.002

Porter, S., Crozier, K., Sinclair, M., & Kernohan, W. (2007). New midwifery? A qualitative analysis of midwives' decision-making strategies. *Journal of Advanced Nursing*, 60(5), 525-534. doi:10.1111/j.1365-2648.2007.04449.x

Reed, R., Sharman, R., & Inglis, C. (2017). Women's descriptions of childbirth trauma relating to care provider actions and interactions. *BMC Pregnancy Childbirth*, 17(1), 21. doi:10.1186/s12884-016-1197-0

Rule, P., & John, V. (2015). A necessary dialogue: Theory in case study research. *International Journal of Qualitative Methods*, 1-11. doi:10.1177/1609406915611575

Schoot, T., Proot, I., ter Meulen, R., & de Witte, L. (2005). Recognition of client values as a basis for tailored care: the view of Dutch expert patients and family caregivers. *Scandinavian Journal of Caring Science*, 19(2), 169-176. doi:10.1111/j.1471-6712.2005.00327.x

Stiggelbout, A., Van der Weijden, T., De Wit, M., Frosch, D., Legare, F., Montori, V., . . . Elwyn, G. (2012). Shared decision making: really putting patients at the centre of healthcare. *British Medical Journal*, 344, e256. doi:10.1136/bmj.e256

Todd, A., Ampt, A., & Roberts, C. (2017). "Very Good" Ratings in a survey of maternity care: Kindness and understanding matter to Australian women. *Birth*, 44(1), 48-57. doi:10.1111/birt.12264

Tulloch, J., & Lupton, D. (2003). *Risk and everyday life*. London: Sage.

VERBI Software GmbH. (2017). *MAXQDA software for qualitative data analysis*. Berlin, Gemany.

Yin, K. (2014). *Case study research: Design and methods*. London: Sage.

Part 2

The TEACH-study

"Women carry their babies for nine months,
but their birth stories for a lifetime."
(Tessa Kowaliw, health consumer advocate, AUS)

8

Preventing traumatic childbirth experiences: 2192 women's perceptions and views.

Arch Womens Ment Health. 2017 Aug;20(4):515-523.
Martine Hollander, Eline van Hastenberg, Jeroen van Dillen, Mariëlle van Pampus, Esteriek de Miranda and Claire Stramrood.

Abstract

Purpose

To explore and quantify perceptions and experiences of women with a traumatic childbirth experience, in order to identify areas for prevention and to help midwives and obstetricians improve woman centered care.

Methods

A retrospective survey was conducted online among 2192 women with a self-reported traumatic childbirth experience. Women were recruited in March 2016 through social media, including specific parent support groups. They filled out a 35-item questionnaire of which the most important items were (1) self-reported attributions of the trauma, and how they believe the traumatic experience could have been prevented (2) by the caregivers or (3) by themselves.

Results

The responses most frequently given were (1) *lack and/or loss of control (54.6%), fear for baby's health/life (49.9%), and high intensity of pain/ physical discomfort (47.4%),* (2) *communicate/explain (39.1%), listen to me (more) (36.9%) and support me (more/better) emotionally/practically (29.8%),* and (3) *nothing (37.0%), ask for (26.9%) or refuse (16.5%) certain interventions.* Primiparous participants chose *High intensity of pain/physical discomfort, Long duration of delivery* and *Discrepancy between expectations and reality more often and Fear for own health/life, A bad outcome and Delivery went too fast* less often than multiparous participants.

Conclusions

Women attribute their traumatic childbirth experience primarily to lack and/or loss of control, issues of communication and practical/emotional support. They believe that in many cases their trauma could have been reduced or prevented by better communication and support by their caregiver, or if they themselves had asked for or refused interventions.

Introduction

Giving birth can be a traumatic experience for women. The extreme outcome of a traumatic birth experience, posttraumatic stress disorder (PTSD), has been an increasingly popular topic of research (Ayers 2004, Grekin and O'Hara 2014, Ayers et al. 2016, Soet et al. 2003, O'Donovan et al. 2014, Stramrood et al. 2011, Rijnders et al. 2008, Elmir et al. 2010, Harris and Ayers 2012). A recent meta-analysis of 78 studies found the prevalence of postpartum PTSD due to childbirth to be 2.9% in community samples (Grekin and O'Hara 2014). A recent systematic review on risk factors for PTSD following childbirth, divided these into pre-birth, during birth, and postpartum risk factors (Ayers et al. 2016). The strongest pre-birth factors were depression in pregnancy, fear of childbirth, poor health or complications in pregnancy, and a history of PTSD. Risk factors during birth were negative subjective birth experiences, having an operative birth (unplanned Cesarean section or operative vaginal delivery), lack of support and dissociation. Post birth risk factors associated with PTSD were poor coping, stress and depression. Prospective studies into predictors of 'finding birth traumatic' found similar factors (Soet et al. 2003, O'Donovan et al. 2014). Researchers have thus far mainly focused on women who developed postpartum PTSD, while they are part of a much larger group of women (9.1-45.5%) who experienced their delivery as traumatic (O'Donovan et al. 2014, Stramrood et al. 2011, American Psychiatric Association 2000).

A Dutch study investigating recall of birth experience three years postpartum found that 16.3% of low risk women looked back negatively on their delivery, especially in case of referral from primary to secondary care (Rijnders et al. 2008).

Why do so many women experience birth as traumatic? A meta-ethnography of ten qualitative studies for which women had been interviewed about their traumatic birth experiences found as most important themes topics concerning communication, being seen as a person and taken seriously, and emotional support during labor (Elmir et al. 2010).

Quantitative measures on attributions and prevention of traumatic delivery experiences could supplement and extend current knowledge, which is thus far based on qualitative studies of perceptions and experiences, and quantitative studies of risk factors. Therefore, the objectives of this study were to identify (1) women's attributions of their trauma, (2) what they feel their caregivers could have done differently, (3) what they themselves could have done to prevent the trauma, and (4) differences between primi- and multiparous women.

Methods

Setting/research design

In the Netherlands, the maternity care system is divided into primary care and secondary care. Low risk women receive care from independent community midwives during pregnancy and delivery (primary care). High-risk women (or those who become so) are cared for in an obstetrician-led hospital setting (secondary care). Referral from primary to secondary care takes place when complications arise at any point or if an increased risk of complications is anticipated, as indicated by national guidelines (CVZ 2003).

For this study, permission was sought from and waived by the medical ethics committee of the Radboud University Nijmegen.

A retrospective survey was conducted among women with one or more self-reported traumatic birth experience. Data were collected in March 2016.

Participants

Women were eligible for participation if they were at least 18 years old, able to complete a Dutch questionnaire and if their traumatic childbirth experience occurred in or after 2005.

Materials

The questionnaire was made available via Survey Monkey. Questions were based on themes and risk factors identified in the literature (Grekin and O'Hara 2014, Ayers et al. 2016, Soet et al. 2003, O'Donovan et al. 2014, Stramrood et al. 2011, Rijnders et al. 2008, Elmir et al. 2010, Harris and Ayers 2012), with emphasis on the findings by Ayers et al (2016) and Elmir et al (2010). The questionnaire was designed specifically for the purpose of this study and contained 35 items in total. In addition to items concerning medical details and basic demographic characteristics of the participants, the three main questions concerned the participants' attribution of their trauma, what they thought their caregivers could have done to prevent the trauma, and what, if anything, they themselves had wanted to do differently. Given options ended with the option *other*. Participants were invited to explain their responses in a free text field. For questions (2) and (3) a maximum of three possible responses was set and participants had to rank their chosen answers, numbering them 1-3. It also contained questions about postpartum follow-up as well as validated questionnaires on posttraumatic stress (PCL-5), coping (sense of coherence) and social support (Oslo social Support Scale, OSS-3). The results of these questionnaires are the subject of a second paper from this study.

To improve the quality of the questionnaire it was reviewed by members of the CAPTURE group (Childbirth and Psychotrauma Research Group), the Committee for Patient Communication of the Dutch Association of Obstetrics & Gynaecology (*Commissie Patiëntencommunicatie NVOG)* and the committee currently designing a Dutch national guideline on PTSD following childbirth and traumatic birth experiences. Furthermore, it was pilot tested by two women who had a traumatic birth experience themselves to identify potential problems with Survey Monkey, unclear instructions or other content issues.

Procedures

The invitation to participate in the study read: "Did you have a traumatic birth experience? If so, please fill out this questionnaire." The question was framed this way on purpose, so it would be clear to the participants that the subject of the study was emotional trauma, not physical. In addition, in the Netherlands, the word trauma is generally understood by lay people as psychological trauma. There were no selection criteria about the nature of the emotional trauma or its intensity. If the participants deemed their experience traumatic they were eligible for inclusion.

Participants were recruited through online invitations posted on a website created for the purpose of this study (www.traumatischebevalling.nl), a Facebook page (www.facebook.com/traumatischebevalling) and a Twitter account (@BevallingTrauma). Midwives and gynecologists in the authors' own networks were approached and requested to share the invitations on social media. Furthermore, the invitation was frequently shared by various other professionals (such as women's coaches, EMDR (Eye Movement Desensitisation and Reprocessing)-therapists, psychiatrists, psychologists and lactation consultants) and by lay people, as well as by the Royal Dutch Organisation of Midwives (KNOV) and the Netherlands Association of Obstetrics and Gynaecology (NVOG). In total, the first Facebook invitation on the page created for this study was shared 243 times and reached 28510 Facebook users. The invitation was, at our request, also posted on pages of several Dutch support groups for pregnancy and childbirth such as the Birth Movement (*Geboortebeweging)*, Traumatic Childbirth and Postpartum Depression group (*Traumatische Bevalling & Postnatale Depressie),* HELLP Syndrome Foundation *(HELLP Stichting)* and Association for Parents of Incubator Babies (*Couveuseouders).*

The filled out questionnaires were imported from Survey Monkey into SPSS version 22 (IBM Corporation Inc., Armonk, NY, USA). Descriptive statistics were used to summarize the characteristics and opinions of the study subjects. Chi-square tests were used to examine associations between patient's characteristics and their attributions of the trauma. Difference between multiple groups

were compared using analyses of variance (ANOVA), with the Games-Howell test being used as post hoc analysis. P-values of less than or equal to 0.05 were considered significant. Women's responses in regard to frequency and ranking were compared for parity (primipara/multipara), level of care during delivery (primary care/secondary care/referral) and educational methods used to prepare for delivery. They were also compared to overall statistics in the Dutch National Perinatal Registry (Brouwers 2014).This was done in order to (1) compare sample characteristics to population characteristics to determine if a representative sample had been obtained and (2) evaluate whether previously known risk factors for PTSD following childbirth (e.g. preterm birth, instrumental delivery, emergency cesarean section) were indeed more prevalent in the current sample than in the general population.

Results

The total number of questionnaires started was 2634. After removing doubles (based on IP-address), participants who had given birth before 2005, participants with impossible answers (e.g. cesarean section at home) and participants who quit the questionnaire before the main question on the cause of the traumatic experience, 2192 responses remained for analysis. The characteristics of the participants are shown in Table 1. Comparison with maternal characteristics from the Dutch Perinatal Registry is shown in the last column (Brouwers 2014). The study population differs significantly in ethnicity, parity, gestational age at delivery, mode of delivery and level of care during pregnancy and delivery compared to the general population.

Attribution of trauma

Most frequently perceived causes of or contributions to the traumatic experience, were *Lack and/or loss of control* (54.6% of participants), *Fear for baby's health/life* (49.9%), *High intensity of pain/ physical discomfort* (47.4%) and *Communication / explanation* (43.7%). An overview of the answers is shown in Table 2 in descending order of frequency and extended with stratification by parity. This stratification shows that primiparous participants chose *High intensity of pain/ physical discomfort, Long duration of delivery* and *Discrepancy between expectations and reality* more often and *Fear for own health/life*, *A bad outcome* and *Delivery went too fast* less often than multiparous participants.

In the category *"Other"* many answers fit into three extra topics: *Separated from baby after delivery*, *Delivery went too fast* and *Have not experienced the delivery consciously (due to general anaesthesia or other medication).*

Of the 51 participants whose baby had died, 62.7% appointed *A bad outcome* as one of the causes of their traumatic experience. The remaining 37.3% mainly reported *Lack and/or loss of control*, *Communication / explanation*, *Respect / taken seriously / way they were treated* and *Lack of emotional and/or practical support from caregivers*.

The answer *Discrepancy between expectations and reality* was chosen significantly more often as cause of trauma when the preparation methods *Hypnobirthing* and/or *Reading in books or on the internet* were used, than when these preparation methods were not used (51.7% vs. 33.8%, p=0.004, and 36.4% vs. 31.1%, p=0.010). For other preparation methods, there were no significant differences in how often *Discrepancy between expectations and reality* was perceived as cause of trauma.

Improvement in caregiver management

Participants were asked what their caregiver could have done to prevent the traumatic birth experience. A minority of 12.4% indicated that the caregiver could have done *nothing* to prevent the trauma. *Communicate/explain* (39.1%) and *Listen to me (more)* (36.1%) were the most frequently chosen answers, followed by *Support me (more/better) emotionally/practically* (29.8%), as shown in Table 3. Examples of lack of emotional or practical support given by women in the free text fields included not being taken seriously in their perception of the speed of labor progression, being left alone during labor, no continuity of care and a midwife or gynecologist who was too busy to spend time with them. The answers most often ranked as the most important in this category were *Listen to me (more)* (20.6%) and *Communicate/explain* (19.7%). Stratification by parity showed that primiparous women listed *Discuss expectations / birth plan*, *Communicate/explain* and *Do certain actions/interventions later/not at all* significantly more often than multiparous women. Multiparous women chose the options *Nothing* and *Listen to me (more)* significantly more often than primiparous women. Examples of commentaries of women in reference to the answer *Discuss expectations/birth plan* were that their birth plan was not taken seriously, that they had not been realistically informed about the likelihood of certain interventions or outcomes and that their antenatal course downplayed the actual pain involved ("painting a rosy picture").

Table 1 Characteristics of the women

Characteristic	Participants N (%) or mean{SD}	95% Confidence interval	Dutch perinatal registry[a]
Age (n=2192)			
At time of survey	33.1 {5.5}		
At time of (traumatic) birth	29.6 {4.4} *		31.0 yr {4.9}
Gestational age at time of traumatic child birth			
16 - 32 weeks	133 (6.1)		>22 wks: 1.5[b]
32 - 37 weeks	243 (11.1) *	9.8 – 12.4	6.1
37 - 42 weeks	1688 (77.0) *	75.2 – 78.8	89.8
> 42 weeks	127 (5.8) *	4.8 – 6.8	1.3
Unknown	N/A		1.3
Years since traumatic child birth			
< 2 years	999 (45.6%)		
2-5 years	684 (31.2%)		
5-12 years	509 (23.2%)		
Ethnicity (n=2192)			
Dutch	2004 (91.4) *	90.2 – 92.6	74.3
not Dutch	188 (8.6) *	7.4 – 9.8	25.7
Parity at time of survey (n=2178)			
Mean parity	1.66 {0.8} *		1.71[c]
Parity at time of traumatic birth experience (n=2178)			
Primiparous	1737 (79.8) *	78.1 – 81.5	45.2
Multiparous	441 (20.2) *	18.5 – 21.9	54.8

Responsible caregiver during pregnancy (n=2180)			
Midwife	1146 (52.6)	50.5 – 54.7	50.7
Obstetrician	345 (15.8)	14.3 – 17.3	14.6
Both (referral from primary to secondary care during pregnancy)	677 (31.1) *	29.2 – 33.0	34.7
Mode of delivery (n=2176)			
Spontaneous vaginal delivery	919 (42.2) *	40.1 – 44.3	74.9
Operative vaginal delivery	577 (26.5) *	24.6 – 28.4	8.7
Secondary Caesarean section	627 (28.8) *	26.9 – 30.7	8.6
Primary Caesarean section	53 (2.4) *	1.8 – 3.0	7.8
Responsible caregiver during delivery (n=2147)			
Midwife (primary care)	122 (5.7) *	4.7 – 6.7	27.4
Obstetrician-led (secondary care)	1098 (51.1)	49.0 – 53.2	49.4
Both[d] (referral during labor or directly postpartum)	927 (43.2) *	41.1 – 45.3	23.2

* Significantly different from Dutch perinatal registry, $p \leq 0.05$
[a] Source, unless otherwise specified: Dutch Perinatal Registry (Brouwers 2014)
[b] Data collection starts at 22 weeks gestation, so no data between 16 and 22 weeks are known.
[c] 'Mean parity' (CBS 2014).
[d] Referral from primary to secondary care

Table 2 Women's attributions of the traumatic birth experience

(in descending order of frequency and stratified by parity; Participants could choose multiple answers, there was no maximum number of answers)

Answer given	n	%	Primiparous	Multiparous	p-value
Lack and/or loss of control	1196	54.6%	961 (55.3%)	226 (51.2%)	0.13
Fear for baby's health/life	1093	49.9%	846 (48.7%)	235 (53.3%)	0.09
High intensity of pain/ physical discomfort	1039	47.4%	850 (48.9%)	184 (41.7%)	0.01 *
Communication / explanation	957	43.7%	773 (44.5%)	178 (40.4%)	0.12
Long duration of delivery	830	37.9%	746 (42.9%)	78 (17.7%)	0.00 *
Lack of emotional and/or practical support from caregivers	781	35.6%	620 (35.7%)	154 (34.9%)	0.76
A certain action/intervention was done	758	34.6%	608 (35.0%)	145 (32.9%)	0.40
Discrepancy of expectations	751	34.3%	617 (35.5%)	133 (30.2%)	0.03 *
(Lack of) Autonomy / involvement in decision-making process	664	30.3%	513 (29.5%)	146 (33.1%)	0.15
Fear for own health/life	633	28.9%	476 (27.4%)	155 (35.1%)	0.00 *
Respect / taken seriously / way they were treated	487	22.2%	375 (21.6%)	106 (24.0%)	0.27
Bad outcome (impactful maternal/infant complications)	444	20.3%	334 (19.2%)	108 (24.5%)	0.01 *
A certain intervention was not done, while the woman would have wanted it to be	382	17.4%	293 (16.9%)	87 (19.7%)	0.16
Lack of emotional support from partner	178	8.1%	134 (7.7%)	42 (9.5%)	0.21
Other					
Separated from baby after delivery	36	1.6%	32 (1.8%)	4 (0.9%)	0.17
Delivery went too fast	34	1.6%	21 (1.2%)	13 (2.9%)	0.01 *
Have not experienced the delivery consciously (due to general anesthesia or other medication)	25	1.1%	22 (1.3%)	3 (0.7%)	0.30
Other reasons	93	4.2%	34 (4.9%)	7 (3.9%)	0.57

Table 3 What women believe caregivers could have done to prevent the traumatic birth experience

(In descending order of frequency and stratified by parity; participants could choose and rank multiple answers, with a maximum of three)

Answer given	n	%	Primiparous	Multiparous	p-value
Communicate / explain	718	39.1%	587 (40.2%)	126 (33.2%)	0.01 *
Listen to me (more)	678	36.9%	515 (35.3%)	160 (42.2%)	0.01 *
Support me (more/better) emotionally / practically	547	29.8%	445 (30.5%)	97 (25.6%)	0.06
Do certain actions/interventions sooner	454	24.7%	367 (25.1%)	86 (22.7%)	0.33
Discuss expectations / birth plan	311	16.9%	271 (18.6%)	39 (10.3%)	0.00 *
Do certain actions/interventions later / not at all	286	15.6%	242 (16.6%)	43 (11.3%)	0.01 *
Don't do anything without my permission	252	13.7%	207 (14.2%)	44 (11.6%)	0.19
Nothing	228	12.4%	164 (11.2%)	61 (16.1%)	0.01 *
Remain calm	228	12.4%	175 (12.0%)	53 (14.0%)	0.29
Other	54	2.9%	22 (3.2%)	7 (3.9%)	0.63

Improvement in self management

The most frequently chosen answer to the question what participants wanted to have done themselves to prevent the trauma or decrease its impact, was *Nothing* (37.0%)(Table 4). *Ask for certain actions/interventions* (26.9%) and *Refuse certain actions/interventions* (16.5%) were also mentioned frequently. Analysis of the ranking in importance of the given answers identified the same top three. Some examples of actions/interventions mentioned in the free text fields were cesarean section, pain relief, vaginal examinations and operative vaginal delivery. Stratification by parity showed that primiparous women chose *Be (better) prepared*, *Make a (better) birth plan* and *Refuse certain actions/interventions* more frequently and *Nothing* less frequently than multiparous women. After analysing themes among frequently mentioned answers within the option *Other*, the categories *Be assertive /express myself / remain in charge* and *Make different choices in caregiver* were added.

Other results

After the traumatic childbirth experience, 48.1% of women had a postpartum check-up with the caregiver who attended the delivery, 36.9% with another caregiver and 15.0% did not have a check-up at all. Of those who did not have a check-up, 4 out of 5 indicated they were not invited and 1 out of 5 chose not to go. Of the women who did have a check-up, 42.0% were asked by the caregiver how they had experienced the delivery and 31.6% brought up the subject themselves. In the remaining 26.4%, the experience of the delivery was not discussed. When the traumatic experience was mentioned by the woman herself, 23% of the caregivers did nothing with this information and some participants added in the free text field that they felt their experience was downplayed (2.3%). According to participants, caregivers might have helped them better if they would have evaluated the experience more thoroughly (62.0%), or if they would have referred them for treatment of the trauma (28.7%).

Almost half of the participants (41.0%) considered filing a complaint against their caregiver and 7.2% actually did. Of those participants who had a postpartum check-up with the same caregiver who assisted in their delivery, 39.5% considered filing a complaint, versus 54.1% who had the check-up with a different caregiver. This difference was significant ($p=<0.001$).

Within the group of participants who had a postpartum check-up without discussing the traumatic experience, 21.3% reported that this was due to the check-up being too soon after the delivery. They explained they couldn't talk about it yet or they didn't yet realise that it was a trauma.

Finally, outcome was compared for level of care during delivery. Participants were stratified into one of three categories: those who received only primary

Table 4 What women wished they had done themselves to prevent the traumatic childbirth

(In descending order of frequency and stratified by parity; participants could choose and rank multiple answers, with a maximum of three)

Answer given	n	%	Primiparous	Multiparous	p-value
Nothing	677	37.0%	501 (34.7%)	170 (45.6%)	0.00 *
Ask for certain actions/interventions	491	26.9%	400 (27.7%)	89 (23.9%)	0.14
Refuse certain actions/interventions	302	16.5%	252 (17.4%)	49 (13.1%)	0.05 *
Be (better) prepared	293	16.0%	254 (17.6%)	38 (10.2%)	0.00 *
Remain (more) calm / accept	266	14.6%	214 (14.8%)	50 (13.4%)	0.49
Make a (better) birth plan	243	13.3%	211 (14.6%)	32 (8.6%)	0.00 *
Ask support from partner	168	9.2%	142 (9.8%)	26 (7.0%)	0.09
Other					
Be assertive / express myself / remain in charge	91	5.0%	71 (4.9%)	19 (5.1%)	0.89
Make different choices in caregiver	62	3.4%	41 (2.8%)	21 (5.6%)	0.01 *
Other answers	55	3.0%	27 (3.9%)	9 (5.1%)	0.50

(midwife-led) care (A), those who started their delivery in primary care but were transferred to secondary (obstetrician-led) care during the delivery or immediately postpartum (B), and those who started their delivery in secondary care (C). Concerning perceived cause of the trauma, eight answers showed significant differences between the groups: *Communication / explanation* (A=32.0%, B=44.6%, C=44.3%; AvsB:p=0.02 ; AvsC:p=0.02; BvsC:p=0.99) and *A certain intervention was done* (A=23.0%, B=35.4%, C=35.7%; AvsB:p=0.01; AvsC:p=0.01; BvsC:p=0.99) were chosen significantly less often in the primary care group (A) than in the other two groups. Women who were transferred during labor (B) reported *a Long duration of delivery* (A=22.1%, B=48.7%, C=30.8%; AvsB:p=0.00; AvsC:p=0.08; BvsC:p=0.00) significantly more often than those who received solely primary or secondary care. The secondary care receivers (C) reported *Fear for own health/life* (A=18.0%, B=25.4%, C=33.1%; AvsB:p=0.13; AvsC:p=0.00; BvsC:p=0.00) significantly more often and *High intensity of pain/ physical discomfort* (A=59.0%, B=49.6%, C=44.4%; AvsB:p=0.12; AvsC:p=0.01; BvsC:p=0.05) significantly less often than the other two groups. *Fear for baby's health/life* (A=35.2%, B=47.0%, C=54.1%; AvsB:p=0.03; AvsC:p=0.00; BvsC:p=0.00)*, the Delivery went too fast* (A=7.0%, B=0.0%, C=2.0%; AvsB:p=0.01; AvsC:p=0.04; BvsC:p=0.01)and *A bad outcome* (A=9.0%, B=18.4%, C=22.8%; AvsB:p=0.00; AvsC:p=0.00; BvsC:p=0.04) significantly differed between all three groups separately.

Regarding advice to caregivers in order to prevent traumatic delivery experiences, participants who received solely primary care (A) answered *Communicate/ explain* significantly less often than those who received solely secondary care (A=27.6%, B=38.9%, C=40.7%; AvsB:p=0.054; AvsC:p=0.02; BvsC:p=0.74). With respect to what participants could have done to prevent the traumatic experience, two significant differences were found between participants who received solely secondary care (C) and those who were referred during labor (B): referred participants chose *Remain calm/ accept* (A=14.0%, B=17.1%, C=12.8%; AvsB:p=0.77; AvsC:p=0.90; BvsC:p=0.04) more often and less often reported *Nothing* (A=33.0%, B=33.2%, C=40.3%; AvsB:p=1.00; AvsC:p=0.32; BvsC:p=0.01).

Discussion

Main findings

Women attribute the cause of their traumatic birth experience primarily to lack and/or loss of control and issues of communication and practical/emotional support. They believe that in many cases their trauma could have been reduced or prevented by better communication and support by their caregiver, or if they themselves had asked for more or fewer interventions.

Strengths and limitations

The design of this study created the opportunity to quantify the opinions of a much larger sample than has ever been reported in previous qualitative studies. The answer options to the most important questions were based on themes and risk factors identified in previous studies, with the extra option 'Other' and room for explanation, which ensured no major themes were missed. Disseminating the questionnaire online through social media proved an efficient way to reach many women with a traumatic birth experience. In January 2016 85% of the Dutch population within the age category 20-39 years old used Facebook (Van der Veer et al. 2016). More than 95% of women giving birth in the Netherlands, 175.181 in 2014 (CBS 2016,) fall within this age category (Brouwers 2014).

Limitations of the study include the inability to generalize findings to all women with a traumatic birth experience due to self-selection of the participants. Certain groups of women may have responded in disproportionate numbers to the recruitment posts. For instance, women with strong convictions about mismanagement of their labor, as well as women who had sought psychological help could have been more attracted to fill out the survey than women who had found a way to successfully process their experience or who felt safe and well supported irrespective of an adverse outcome. In addition, we cannot rule out the possibility that some women who experienced physical trauma during their delivery misunderstood the invitation and filled out the questionnaire, when in fact they did not experience any emotional trauma. However, in the Netherlands, the word trauma in lay terms is generally understood to mean psychological trauma. Therefore we believe we can safely assume most participants interpreted our invitation correctly. Also, more than half of the participants report on a delivery that occurred more than two years ago, making recall bias a distinct possibility. The fact that the study took place in the Netherlands, with its unique obstetrical model, may impact on its generalizability. However, many findings are in accordance with previous (qualitative) studies done elsewhere, including need for better emotional support and sense of control. Non Dutch speaking women were excluded, leaving out important groups such as immigrants and

functional illiterates, who potentially carry higher risks of traumatic birth experiences due to communication difficulties.

Discussion of the main findings

Lack and/or loss of control was most often perceived as a major cause of trauma. This is in line with some previous studies where lack and/or loss of control was identified as a risk factor for PTSD and for experiencing birth as traumatic (Grekin and O'Hara 2014, Ayers et al. 2016, Soet et al. 2003, O'Donovan et al. 2014). This finding was strengthened by 37% of participants reporting that there was nothing they could have done differently, often adding the remark that the situation was not their fault. Also, these results further support the literature concerning the importance of interactions with caregivers (concerning communication, explanation, listening, emotional and practical support) (Grekin and O'Hara 2014, Ayers et al. 2016, Elmir et al. 2010, Harris and Ayers 2012). When situations are thoroughly and clearly explained, fear might decrease, especially for those women who explained their fear was due to not knowing what was happening and why (Vandevusse 1999), which was also an explanation various participants gave to lack or loss of control. Providing information seems important not only during labor itself, but also during pregnancy, as is shown by the number of women who listed *Discuss expectations/birth plan* as a point of improvement for their caregiver. Pain might also decrease with good practical and emotional support from caregivers, as concluded by a Cochrane review finding that continuous support during labor decreases the risk of receiving analgesia and is associated with fewer negative birth experiences (Hodnett et al. 2013).

Another interesting finding was that *preparation for birth with hypnobirthing* was strongly associated with a discrepancy between expectations of the delivery and the reality as cause of the trauma. This raised the question whether this particular approach to birthing adequately prepares women for the reality of labor. However, one could also hypothesize that choice of birthing class could be influenced by expectations or even personality, so this finding would need to be re-examined in a randomized setting. The effects of hypnobirthing, where the woman and her partner are taught self-hypnosis during labor and are told that childbirth does not have to be painful, on delivery and patient satisfaction have not yet been studied in depth (Cyna et al. 2013, Finlayson et al. 2015).

Interpretation

In previous Dutch studies, referral from primary to secondary care during labor has already been linked to experiencing loss of control (Geerts et al. 2014), and was found to be associated with both a negative birth experience ten days postpartum and negative recall after three years (Rijnders et al. 2008, Kleiverda

et al. 1991). In line with this finding, the present study comprises significantly more referred women (43%) than the general population (23%). Our sample also contained significantly fewer exclusively primary care receivers (6%) than the general population (27%), which fits with previous research (Stramrood et al. 2011). There are two likely explanations for this. Firstly, complications and interventions are associated with traumatic delivery experiences and PTSD (Grekin and O'Hara 2014, Ayers et al. 2016, Soet et al. 2003, Stramrood et al. 2011), and many interventions are not possible in primary care (e.g. cesarean section, instrumental delivery, epidural analgesia, induction of labor). Lower rates of trauma in primary care are the logical consequence. Secondly, when women are referred they will usually encounter a new and unfamiliar team of obstetric care providers, which could influence the quality of patient-provider interaction.

Studies concerning risk factors for PTSD and traumatic or negative birth experiences consistently found operative births (operative vaginal deliveries and cesarean sections) to be a risk factor (Ayers et al. 2016, Soet et al. 2003, Stramrood et al. 2011, Rijnders et al. 2008). Interestingly, while the high prevalence of operative births among our participants suggests the same association, the interventions themselves -being ranked seventh- were not among the most frequently reported causes of trauma. Rather, the traumatic nature of operative births might be linked to the interactions around it, such as the indication for the intervention or the procedure itself not being explained, the woman being insufficiently supported or inadequately prepared for the realities of childbirth. The idea of 'interactions rather than interventions' is further supported by the answers from a considerable proportion of the women who had lost their baby. More than one in three participants whose baby died did not report this as a cause of the trauma. Instead, they reported lack and/or loss of control and shortcomings in the interaction with caregivers (communication, respect and support). This is in line with a recent study among Australian midwives, which found that they too showed stronger reactions to the trauma of disrespectful interpersonal interactions between women and caregivers than to physical trauma or even death (Leinweber et al. 2017).

Expectations appeared to be an important issue for primiparous participants in our study. Caregivers should discuss realistic expectations of delivery during pregnancy and pay sufficient attention to preparation and birth plans. This study also demonstrates that women who have experienced their birth as traumatic do not always receive a postpartum check-up with the caregiver who was present during the birth. This may contribute to underdiagnosis and undertreatment, and is a missed opportunity for reviewing the course and experience of giving birth with the caregiver who was present. We recommend that every woman should be offered a postpartum visit with the caregiver who assisted her during their delivery.

Conclusion

The most important items identified by 2192 women with a traumatic birth experience were lack and/or loss of control and interaction with caregivers (concerning communication/explanation, listening, emotional and practical support). Interaction around interventions seemed to be more important than the interventions themselves, which is crucial information for obstetric care providers to be aware of. Referral from primary to secondary care occurred more often in this group than average in the Dutch birth registry. There is a definite need for attention to and improvement of communication and interaction between patient and caregiver, not only during antenatal care and labor, but also during postpartum follow-up.

The findings from this study should form a basis for future research and policy aimed at reducing and preventing traumatic delivery experiences. Further research is needed regarding optimal ways (information provided and courses offered) to prepare women for the reality of birth.

Future studies on the effects of continuity of care(give)r should pay special attention to the experiences and opinions of women who experienced referral during childbirth.

References

American Psychiatric Association: Washington DC. Diagnostic and statistical manual of mental disorders (4th edn.-Text Revision). 2000

Ayers S. Delivery as a traumatic event: prevalence, risk factors, and treatment for postnatal posttraumatic stress disorder. Clin Obstet Gynecol. 2004; 47(3): 552-67

Ayers S, Bond R, Bertullies S, Wijma K. The aetiology of post-traumatic stress following childbirth: a meta-analysis and theoretical framework. Psychol Med. 2016; 46(6): 1121-34

Brouwers H. Perinatal Care in the Netherlands 2013. Utrecht: Foundation Perinatal Registration the Netherlands, 2014

CBS (Central Bureau of Statistics), the Hague/Heerlen 2014

CBS website accessed 12-6-2016: http://statline.cbs.nl/statweb/publication/?vw=t&dm=slnl&pa=37422ned&d1=0,4-5,7,9,11,13,17,26,35,40-41&d2=0,10,20,30,40,(l-4)-l&hd=090218-0953&hdr=g1&stb=t

CVZ (College for Health Care Insurance): Diemen, the Netherlands. Verloskundig Vademecum 2003.

Cyna AM, Crowther CA, Robinson JS, Andrew MI, Antoniou G, Baghurst P. Hypnosis antenatal training for childbirth: a randomized controlled trial. BJOG 2013 Sep; 120(10):1248-59

Elmir R, Schmied V, Wilkes L, Jackson D. Women's perceptions and experiences of a traumatic birth: a meta-ethnography. J Adv Nurs. 2010; 66(10): 2142-53

Finlayson K, Downe S, Hinder S, Carr H, Spiby H, Whorwell P. Unexpected consequences: women's experiences of a self hypnosis intervention to help with pain relief during labor. BMC Pregnancy Childbirth 2015 Sep 25; 15: 229.

Geerts CC, Klomp T, Lagro-Janssen AL, Twisk JW, van Dillen J, de Jonge A. Birth setting, transfer and maternal sense of control: results from the DELIVER study. BMC Pregnancy Childbirth 2014 Jan 17; 14: 27.

Grekin R, O'Hara M.W. Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis. Clin Psychol Rev. 2014; 34(5): 389-401

Harris R, Ayers S. What makes labor and birth traumatic? A survey of intrapartum 'hotspots'. Psychol Health 2012; 27(10): 1166-77

Hodnett ED, Gates S, Hofmeyr G, Sakala C. Cochrane Database of Systematic Reviews 2013(7)

Kleiverda G, Steen AM, Andersen I, Treffers PE, Everaerd W. Confinement in nulliparous women in the Netherlands: Subjective experiences related to actual events and to post-partum well-being. J Reprod Inf Psychol. 1991; 9(4): 195-213

Leinweber J, Creedy DK, Rowe H, Gamble J. A socioecological model of posttraumatic stress among Australian midwives. Midwifery. 2017 Feb;45:7-13.

O'Donovan A, Alcorn KL, Patrick JC, Creedy DK, Dawe S, Devilly GJ. Midwifery 2014; 30(8): 935-41

Rijnders M, Baston H, Schönbeck Y, van der Pal K, Prins M, Green J et al. Perinatal factors related to negative or positive recall of birth experience in women 3 years postpartum in the Netherlands. Birth 2008; 35(2): 107-16

Soet JE, Brack GA, Dilorio C. Prevalence and predictors of women's experience of psychological trauma during childbirth. Birth 2003; 30(1): 36-46

Stramrood CA, Paarlberg KM, Huis In 't Veld EM, Berger LW, Vingerhoets AJ, Schultz WC et al. Posttraumatic stress following childbirth in homelike- and hospital settings. J Psychosom Obstet Gynaecol. 2011; 32(2): 88-97

Vandevusse L. Decision making in analyses of women's birth stories. Birth 1999; 26(1): 43-50

Van der Veer N, Sival R, van der Meer I. National Social Media Research 2016. Newcom Research&Consultancy B.V. 2016

9

Psychosocial predictors of postpartum posttraumatic stress disorder in women with a traumatic childbirth experience.

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Abstract

Objective

To analyze the predictive value of antepartum vulnerability factors, such as social support, coping, history of psychiatric disease and fear of childbirth, and intrapartum events on the development of symptoms of postpartum posttraumatic stress disorder (PP-PTSD) in women with a traumatic childbirth experience.

Materials and methods

Women with at least one self-reported traumatic childbirth experience in or after 2005 were invited to participate through various social media platforms in March 2016. They completed a 35-item questionnaire including validated screening instruments for PTSD (PTSD Symptom Checklist, PCL-5), social support (Oslo social support scale, OSS-3) and coping (Antonovsky's sense of coherence scale, SoC).

Results

Of the 1599 women who completed the questionnaire, 17.4% met the diagnostic criteria for current PTSD according to the DSM-5, and another 26.0% recognized the symptoms from a previous period, related to giving birth. Twenty-six percent of the participating women had received one or more psychiatric diagnoses at some point in their life, and five percent of all women had been diagnosed with PTSD prior to their traumatic childbirth experience. Women with poor (OR=15.320, CI=8.001-29.336), or moderate (OR=3.208, CI=1.625-6.333) coping skills were more likely to report PP-PTSD symptoms than women with good coping skills. Low social support was significantly predictive for current PP-PTSD symptoms compared to high social support (OR=5.557, CI=2.967- 7.785). A predictive model which could differentiate between women fulfilling vs. not fulfilling the symptom criteria for PTSD had a sensitivity of 80.8% and specificity of 62.6% with an accuracy of 66.5%.

Conclusions

Low social support, poor coping, experiencing 'threatened death' and experiencing 'actual or threatened injury to the baby' were the four significant factors in the predictive model for women with a traumatic childbirth experience to be at risk of developing PP-PTSD. Further research should investigate the effects of interventions aimed at the prevention of PP-PTSD by strengthening coping skills and increasing social support, especially in women at increased risk of unfavorable obstetrical outcomes.

Introduction

For a long time, childbirth has been regarded by professionals as a positive experience for the mother, but in the past two decades there has been increasing attention in research and clinical practice for women with a negative or even traumatic childbirth experience. In some cases this experience can lead to a postpartum posttraumatic stress disorder (PP-PTSD) (1). Two recent systematic reviews estimated the prevalence of PP-PTSD at 3.1 and 4.0%, in unselected or community samples, respectively (2, 3). A third systematic review suggested a prevalence of 4.9% for PTSD in the first six months after childbirth in women without a prior history of PTSD (4). Additionally, 9.6% of the women in this study had at least some symptoms of PP-PTSD. Literature about women with a self reported traumatic childbirth experience is scarce, despite a reported prevalence of 9.1 to 45.5%. Frequently mentioned attributions of the trauma are lack or loss of control, breeched expectations about giving birth, perception of inadequate intrapartum care, and the level of obstetric intervention experienced during birth (5-7).

The diathesis-stress model is frequently used to understand the risk factors for developing PP-PTSD. This approach implies that the development of PP-PTSD depends on a combination of the degree of antepartum vulnerability, the events during delivery and postpartum factors (8). A previous history of psychiatric disease, depression during the current pregnancy, fear of childbirth and medical complications during childbirth have previously been identified to contribute to antepartum vulnerability for PP-PTSD. Operative birth (unplanned caesarean section and instrumental delivery), dissociation, lack of support by medical staff and loss of control during delivery are also known contributors to the development of PP-PTSD, as well as poor coping after childbirth (9). Many of these factors are also consistent with the known risk factors for a traumatic childbirth experience (7, 10).

Being able to identify antepartum vulnerability factors and events during delivery could be helpful in designing future interventions aimed at reducing the risk of women experiencing giving birth as traumatic and/or preventing the development of PP-PTSD (symptoms). To date, there are only three studies that analyzed risk factors for developing PP-PTSD in women with a traumatic childbirth experience based on criterion A of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (7, 10-12). Two studies aimed to provide predictors for the development of PP-PTSD that could be used for the construction of a screening tool or intervention strategy (7, 10). The most recent study of Dikman-Yildiz et al. (12) investigated the different trajectories of birth-related PTSD and the predictors of each trajectory. This study showed that the

development of PP-PTSD in women with a traumatic childbirth experience could be divided in four trajectories: resilience (61.9%), recovery from PTSD (18.5%), chronic PTSD (13.7%) and delayed PTSD (5.8%).

Recently, a systematic review about prevention of traumatic childbirth experiences and PP-PTSD found that to date there is no study investigating primary prevention of a traumatic childbirth experience. A few studies with insufficient level of evidence have investigated the secondary prevention of PP-PTSD or a traumatic childbirth experience (13). Being able to identify antepartum vulnerability factors and predisposing events during delivery could be helpful in designing future interventions aimed at reducing the risk of women experiencing childbirth as traumatic and/or preventing the development of PP-PTSD (symptoms).

The first objective of the current study was to analyze the role of antepartum vulnerability factors in the development of PP-PTSD symptoms in women with a traumatic childbirth experience, such as social support, sense of coherence, a history of psychiatric disease and fear of childbirth, in addition to events during delivery. The second objective of this study was to make a predictive model using these antepartum vulnerability factors and factors during delivery, which could differentiate between women who have experienced childbirth as traumatic and who are more likely to develop PP-PTSD symptoms. That way, antepartum vulnerability factors and factors during delivery could be identified and future interventions designed to prevent PP-PTSD symptoms could be designed.

Methods

Setting/research design

A retrospective study was carried out among women with at least one self-reported traumatic childbirth experience in the Netherlands between 2005 and 2016. In the Netherlands, maternity care is organized differently from many other high income countries. It is divided into two levels of care: healthy women with a low-risk pregnancy are cared for by independent community midwives during pregnancy and childbirth, while women with (a higher risk of) complications during current or previous pregnancies or women with specific healthcare problems receive care from an obstetrician in a hospital setting. The recommended level of care is based on national guidelines (14).

Participants

Participants were eligible for inclusion in the study if they were 18 years or older, if they had a history of at least one traumatic childbirth experience in the Netherlands between 2005 and 2016 and if they could read and write in Dutch.

Procedure

The participants were invited to fill out an online questionnaire if they had an affirmative response to the question 'Did you have a traumatic birth experience?'. The questionnaire was accessible through SurveyMonkey (15) for a period of three weeks in March of 2016. Participants were recruited through a designated website (www.traumatischebevalling.nl), and a Facebook page and Twitter account created for the purpose of the study. Various Dutch support groups, like the HELLP Syndrome Foundation, Traumatic Childbirth & Postpartum Depression, Birth Movement and Association for Parents of Incubator Babies and two professional associations (Royal Dutch Association Of Midwives (KNOV) and Dutch Association of Obstetrics and Gynaecology (NVOG)), shared the questionnaire on their online pages at our request. Ethical approval for this study was deemed unnecessary by the medical ethics committee of the Radboud University Nijmegen.

Data were collected online and transferred to SPSS version 22 (IBM Corporation Inc., Armonk, NY, USA). Questionnaires with the same IP address (multiple entries) or inconsistent answers (e.g. planned caesarean section during home birth) were excluded from the data set. The results of the first part of the dataset, which concerned women's attributions regarding their traumatic childbirth experience and what their caregiver or they themselves could have done to prevent the trauma, have already been published (16). To be included in the current article, participants had to fill out the complete questionnaire up until and including the last item about Sense of Coherence, which was one of the variables in our study.

Measurements

The questionnaire consisted of items regarding demographic information of the participants, attributions of their traumatic childbirth experience, medical details and various risk factors for PP-PTSD known from literature. The questionnaire also contained four psychological measurement tools (see details below). The first draft of the questionnaire was reviewed by two parties: members of the Childbirth and Psychotrauma Research (CAPTURE) group of the hospital OLVG in Amsterdam, the Netherlands and the committee for patient communication of the NVOG. Presence of criterion A of the DSM-5 (17) was determined through questions about the threat to participants' own life or

the life of others and actual or threatened serious injury to self or others. Threat to participants' physical integrity, which was included in criterion A1 of the DSM-IV but left out of the DSM-5, was determined in order to compare criterion A1 of the DSM-IV with criterion A of the DSM-5.

The Posttraumatic stress disorder CheckList (PCL-5) was developed to measure symptoms of posttraumatic stress disorder according to the DSM-5. The participants were asked to fill out the checklist in relation to their traumatic childbirth experience. The PCL-5 consists of 20 questions corresponding with 20 symptoms of category B (re-experiencing), C (avoidance), D (negative thoughts and feelings) and E (trauma-related arousal and reactivity) of the DSM-5. All statements were followed by five-point Likert scales (range zero to four). A score of two or higher was considered clinically relevant. The criterion was met for category B and C when there was at least one clinically relevant symptom in each category. Two clinically relevant symptoms were needed for category D and E (18). If all four criteria were met in combination with the A-criterion, current PP-PTSD was considered likely.

The Sense of Coherence (SoC) is a validated questionnaire with thirteen items measuring the way in which a person sees the world as comprehensible, manageable, and meaningful (19). Strong SoC is indicative of effective coping strategies. The thirteen items are rated on a seven-point Likert scale, with a total possible score between 13 and 91. The data from the questionnaire were used as continuous variables, but also divided into the three groups used in literature pertaining to SoC and childbirth (20, 21). The groups were defined as follows: a score under 60 points was defined as a low SoC score, a score between 61 and 75 was a moderate score and 76 or higher was a high score.

The social support of a participant was measured with the Oslo Social Support Scale (OSS-3). The OSS-3 is a validated three-item questionnaire with questions about the number of people a participant can count on, how much interest people are showing regarding the participant and how easily the participant could get help from neighbors. The total possible score of the OSS-3 ranges between three and fourteen A score of three to eight indicates poor support, a score of nine to eleven means moderate support and a score of twelve to fourteen signifies high support (22, 23).

Fear of childbirth was measured on a ten-point scale. Measurement of fear of childbirth with a ten-point scale has been validated compared to the W-DEQ questionnaire, which is a validated tool for measuring fear of childbirth. A threshold of 5.0 for a positive score has been demonstrated in literature to have a sensitivity of 97.8% and a specificity of 65.7% in comparison with a score of ≥100 on the W-DEQ questionnaire, signifying extreme fear of childbirth (24).

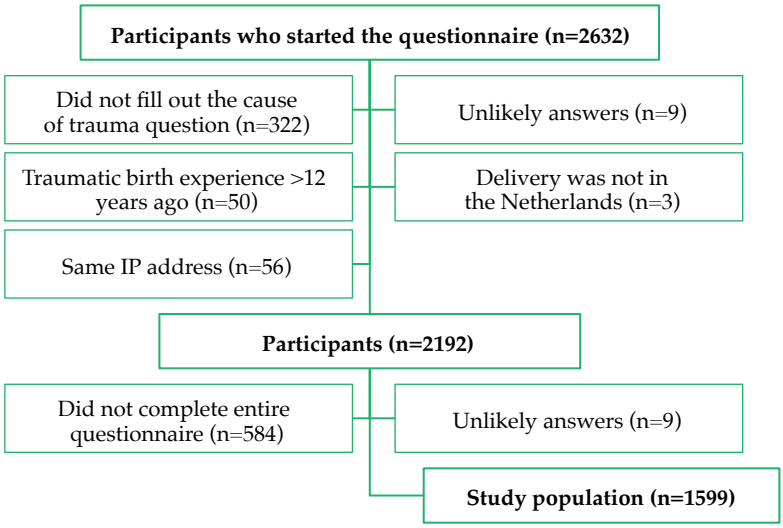
Data analysis

The characteristics of women with a traumatic childbirth experience were summarized by descriptive statistics. Chi square tests were used to compare the characteristics of different groups. Continuous variables (fear of childbirth, Oslo Social Support and Sense of Coherence) were not distributed normally. Therefore, Mann-Whitney U-tests were used for comparative analyses. Logistic regression analyses were used for antepartum vulnerability factors (Sense of Coherence, social support, fear of childbirth, parity, age), factors during delivery (mode of delivery, criterion A of the DSM-5, including threat to physical integrity, and caregiver during delivery). There were no postpartum factors used inour analyses. The ordinal groups for the Sense of Coherence-, Oslo Social Support- and Fear of childbirth analyses were only used in univariable logistic regression analyses. Univariable logistic regression analyses were performed to estimate odds ratios and their 95% confidence intervals for factors associated with symptoms of PP-PTSD (meeting all criteria B, C, D and E for PTSD on the PCL-5). The same analyses were done for women who were treated for PP-PTSD and/or received a diagnosis of PP-PTSD from a psychologist, psychiatrist or general practitioner. A significance level of less than or equal to 0.05 was used. A predictive model was created with a multivariable logistic regression analysis, including only those variables that were statistically significant in univariable logistic regression, while using a backward likelihood ratio method and a logit function (entry -0.05; removal-0.10). This was done to establish predictive factors and determine their respective weight in predicting PP-PTSD. The Nagelkerke R^2, which only gives a relative measure of R^2 in logistic regression analysis, was used to evaluate the predictive power of the different models (25). The maximum value of the Youden index (J=sensitivity + specificity -1) was used to find the point at which the cutoff value of the formula reached optimal sensitivity and specificity, when sensitivity and specificity are given equal weight (26).

Results

A total of 2634 questionnaires were filled out during a three week period in March of 2016. After removal of all questionnaires which did not meet the inclusion criteria for the first article published (16), 2192 questionnaires remained. An extra 584 participants were excluded from this current study, because they did not complete the questionnaire up until and including the last item about Sense of Coherence, which was not required for the previous article (Figure 1). A total of 1599 questionnaires remained after exclusions.

Figure 1 Flowchart of questionnaires excluded from the study



The study population of women with a traumatic childbirth experience was compared to Dutch national data on all childbearing women. The study participants differed significantly from the national data for the same characteristics as published in the article by Hollander et al. (16): lower parity at time of traumatic childbirth experience, older age during childbirth, fewer deliveries between 37-42 weeks, fewer women of non Dutch ethnicity, more unplanned cesarean sections, fewer planned cesarean sections, fewer spontaneous vaginal deliveries and more referrals to a different level of care during pregnancy and delivery.

The basic characteristics of the participants who were excluded from the existing dataset of Hollander et al. (16) because they did not complete the entire questionnaire (n=584) did not differ significantly from the participants that were included, except for their response to the DSM-A criterion: the 584 excluded women less often reported a threat to their own life (24.8% vs. 29.7%, p=0.023), actual or threatened serious injury (26.3% vs. 30.8%, p=0.040) and a threat to their physical integrity (28.3% vs. 38.9%, p<0.001) compared to the women included in the analyses in the current article (n=1599).

Percentage of women meeting DSM criteria for PTSD

A majority of the participants (83.1%) experienced a traumatic childbirth according to criterion A1 of the DSM-IV, which included experienced threats to physical integrity, while 75.0% of the women met criterion A of the DSM-5.

Women who met criterion A of the DSM-5 were significantly more likely to have been diagnosed with PP-PTSD by their general practitioner or a psychiatrist (18.8% vs. 8.6%, p=0.003) compared to women meeting criterion A1 of the DSM-IV who did not meet criterion A of the DSM-5. They were, however, not more likely to get treatment for PTSD (21.7% vs. 14.8%, p=0.072) than women meeting criterion A1 of the DSM-IV who did not meet criterion A of the DSM-5.

Table 1 gives an overview of the percentages of women meeting criteria A, B, C, D and E. The percentages of women meeting criterion B through E ranged between 39.8% and 54.2%. A total of 17.4% (n=278) of participants met all criteria (A, B, C, D and E) based on the DSM-5, whereas 4.1% (n=65) of participants fulfilled criteria B, C, D and E but missed criterion A of the DSM-5. Of these 65 participants, 40.0% (26/65) would have met criterion A1 based on the DSM-IV, meaning that 26 women in this study were deemed not to have PP-PTSD by DSM V criteria, where they would have qualified according to DSM-IV criteria.

Participants were asked if they recognized the symptoms on the PCL-5 questionnaire from earlier, in order to identify women who had experienced

Table 1 The prevalence of criteria A, B, C, D and E for PTSD in the participants

Characteristics (n=1599)	Participants n(%)
Criterion A	
DSM-IV (A1) [a]	1328 (83.1)
DSM-5 (A) [b]	1200 (75.0)
PTSD checklist (PCL-5)	
Criterion B (Re-experiencing)	866 (54.2)
Criterion C (Avoidance)	651 (40.7)
Criterion D (Negative thoughts and feelings)	727 (45.5)
Criterion E (Trauma-related arousal and reactivity)	636 (39.8)
Criterion BCDE	343 (21.5)
Criterion ABCDE (DSM-5)	278 (17.4)
Recognition of symptoms PCL-5	
Recognition [c]	415 (26.0)

[a] Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 4th edition (1994)

[b] American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 5th edition (2013)

[c] I recognize these symptoms from earlier, these had to do with my traumatic childbirth experience (PCL-5)

symptoms of PP-PTSD in the past, but did not have symptoms at the time of completing the questionnaire. Twenty-six percent of the participants recognized these symptoms from an earlier period related to the traumatic childbirth experience.

Table 2 Psychosocial factors of the study population

Antepartum factors (n=1599)	Participants n(%) or mean {SD}
Sense of Coherence (13-91) [a]	
Low Sense of Coherence	713 (44.6)
Moderate Sense of Coherence	617 (38.6)
High Sense of Coherence	269 (16.8)
Mean Sense of Coherence	61.9 {13.1}
Fear of childbirth (1-10)	
Mean fear of childbirth	4.2 {2.3}
Oslo Social Support (OSS-3) (3-14)[b]	
Poor support	311 (19.4)
Moderate support	699 (43.7)
Strong support	589 (36.8)
Mean OSS-3	10.5 {2.3}
History of psychiatric disease	
History of psychiatric disease	420 (26.3)
Depression	223 (13.9)
Posttraumatic stress disorder	80 (5.0)
Anxiety	118 (7.4)
Personality disorder	31 (1.9)
Other	84 (5.3)

[a] Cut–off score Sense of Coherence: Low Sense of Coherence corresponds to 13-60 points, moderate Sense of Coherence 61-75 points, high Sense of Coherence 76-91 points.

[b] Cut-off score Oslo Social Support: Poor support corresponds to 3-8 points, moderate support to 9-11 points, strong support 12-14 points.

Table 3 Psychosocial factors or characteristics of delivery and their association with the occurrence of PP-PTSD symptoms[a]

Predictor	Odds ratio	95% confidence interval
Age of trauma (years)	0.98	0.95- 1.01
First delivery (Multiparous versus primiparous)	0.90	0.67- 1.20
Criterion A (experienced ..)		
Threatened death	2.00 *	1.56- 2.56
Threatened death baby	1.54 *	1.20- 1.97
Actual or threatened injury to self	1.36 *	1.05- 1.74
Actual or threatened injury to the baby	1.70 *	1.33- 2.16
Threat to physical integrity	1.41 *	1.11- 1.79
Caregiver pregnancy		
Midwife	0.76 *	0.60- 0.97
Obstetrician/ Gynaecologist	1.16	0.84- 1.61
Referral	1.19	0.93- 1.53
Caregiver delivery		
Midwife	0.83	0.48- 1.45
Obstetrician/ Gynaecologist	1.22	0.96- 1.55
Referral	0.85	0.67- 1.09
Mode of delivery		
Vaginal delivery	0.92	0.72- 1.18
Instrumental delivery	0.91	0.69- 1.19
Planned cesarean section	1.72	0.83- 3.54
Unplanned cesarean section	1.13	0.87- 1.47
Sense of coherence (SoC)		
Each extra point on SoC	0.92 *	0.91- 0.93
Moderate SoC [b]	3.21 *	1.63- 6.33
Low SoC [b]	15.32 *	8.00- 29.34
Oslo Social Support scale (OSS-3)		
Each extra point on OSS-3	0.75 *	0.71- 0.79
Moderate support [c]	1.92 *	1.41- 2.62
Poor support [c]	5.56 *	3.97- 7.79

Table 3 Continued

Predictor	Odds ratio	95% confidence interval
Fear of childbirth		
Each extra point for fear of childbirth	1.11 *	1.06- 1.17
Fear of childbirth[d]	1.63 *	1.27- 2.09
History of psychiatric disease		
Any history of psychiatric disease	1.66 *	1.28- 2.14
Posttraumatic stress disorder	2.59 *	1.63- 4.12
Depression	1.76 *	1.28- 2.41
Anxiety	1.40	0.92- 2.14
Personality disorder	2.71 *	1.31- 5.59

* Significant at $p \leq 0.05$

[a] Symptoms of PP-PTSD are defined as women meeting all criteria B, C, D and E for PTSD on the PCL-5

[b] Reference group consists of all the participants with a high sense of coherence

[c] Reference group consists of all the participants with a strong support

[d] A cutoff of five points was used on the fear of childbirth scale.

Antepartum vulnerability factors

The antepartum vulnerability factors of the participants are shown in table 2. Sense of Coherence had a mean of 61.9 points for the study population. With a cut-off value of 60 or less for low coping abilities, it was found that almost half of the sample had poor coping abilities (44.6%), whereas 16.8% of participants had good coping abilities. A mean of 4.2 was found on a ten-point scale for fear of childbirth. The OSS-3 had a mean of 10.5 on a 14-point scale and showed that 19.4% of participants had poor social support. Twenty-six percent of the participating women had at some point in their lives received a psychiatric diagnosis unrelated to pregnancy or childbirth, and of all women, five percent had received a diagnosis of PTSD following a trauma other than the traumatic childbirth experience.

Predictors of a diagnosis of PP-PTSD or treatment for PTSD

Women who had a low sense of coherence were more often diagnosed with PP-PTSD by a psychologist, psychiatrist or their general practitioner compared to women with a high sense of coherence (OR=1.811, CI=1.217- 2.697, p=0.003).

However, low sense of coherence was not significantly associated with women who received treatment for PP-PTSD (OR=1.247, CI=0.875 -1.777, p=0.222).

Women who had poor social support were more often diagnosed with PP-PTSD, compared to those with strong social support (OR=1.676, CI=1.181-2.379, p=0.004), although women who had poor social support were not treated for PP-PTSD significantly more often than women with strong social support (OR=0.859, CI=0.606-1.219, p=0.859).

Women with a diagnosis of PP-PTSD (OR=1.315, CI=0.999- 1.731, p=0.051) or who received treatment for PP-PTSD (OR=0.879, CI=0.671- 1.152, p=0.349) were not significantly more likely to have a score above the cutoff of five points on the fear of childbirth scale than those without diagnosis of or treatment for PP-PTSD.

Predictors of current PTSD symptoms

The associations between antepartum vulnerability factors or factors during delivery and reporting PP-PTSD symptoms at time of participation are shown in table 3. Each of the components of criterion A of the DSM-5 is a significant predictor for meeting all of the criteria (B, C, D and E). Threat to physical integrity, which was criterion A1 of the DSM-IV, was a significant predictor for current PP-PTSD symptoms (OR=1.409, CI=1.107-1.794, p=0.005).

Women with a low (OR=15.320, CI=8.001-29.336, p=<0.001), or moderate SoC were more likely to report PP-PTSD symptoms than women with a high SoC (OR=3.208, CI=1.625-6.333, p=0.001). Women with poor (OR=5.557, CI=2.967-7.785, p=<0.001) or moderate social support were more likely to report PP-PTSD symptoms compared to women with high social support (OR=1.921, CI=1.407-2.623, p=<0.001). A cutoff at five points on the fear of childbirth scale was significantly predictive for women reporting PP-PTSD symptoms at time of participation (OR=1.633, CI=1.273- 2.094, p<0.001).

Women with antepartum check-ups in primary care had a significantly lower chance of having PP-PTSD symptoms at time of participation (OR=0.759, CI=0.597-0.966, p=0.025). Women with a history of depression (OR=2.589, CI=1.628-4.120, p<0.001), or PTSD (OR=1.756, CI=1.285-2.405, p<0.001) reported PP-PTSD symptoms significantly more often. Overall, age and parity at the time of the traumatic childbirth experience and mode of delivery were not significantly associated with current PP-PTSD symptoms.

Toward a predictive model for PP-PTSD symptoms

A multivariable logistic regression was performed with the aim of proposing a model for predicting PP-PTSD symptoms in women with a traumatic childbirth experience and to determine their respective weight in predicting PP-PTSD. The proposed model with a Nagelkerke R^2 (25) of 0.275 includes four predictors

(table 4): score on the Sense of Coherence (OR= 0.927, CI=0.916-0.939, p=<0.001), score on the OSS-3 (OR=0.901, CI=0.846-0.961, p=0.001), experiencing 'threatened death' (OR=1.919, CI=1.451-2.537, p<0.001) and experiencing 'actual or threatened injury to the baby' (OR=1.493, CI=1.137-1.960, p=0.004).

Table 4 Variables found to contribute significantly to predicting the occurrence of PP-PTSD symptoms in a multivariable logistic regression analysis

Predictor	Odds ratio	95% confidence interval
Criterion A (experienced ..)		
Threatened death to self	1.92*	1.45- 2.54
Actual or threatened injury to the baby	1.49**	1.14- 1.96
Sense of coherence (SoC)		
Each extra point of SoC	0.93*	0.92- 0.94
Oslo Social Support scale (OSS-3)		
Each extra point of OSS-3	0.90*	0.85- 0.96

* Significant at p ≤ 0.001
** Significant at p ≤ 0.05

A formula for a predictive model for postpartum women meeting the DSM-5 criteria for PTSD (BCDE) was built using the beta coefficient of the variables mentioned above and the constant of the multiple logistic regression analysis. This model has an area under the receiver operating characteristic (ROC) curve of 0.795 (CI=0.769-0.821, p<0.001). The optimum sensitivity of 80.8% and specificity of 62.6% of this predictive model was found at a threshold of -1.57, using the Youden index (26). A score above -1.57 in the formula corresponds to a high possibility of current PP-PTSD symptoms. The accuracy of this model is 66.5% with a threshold of -1.57.

Multiple logistic regression analyses of women with either a diagnosis by a psychologist, psychiatrist or general practitioner of or treatment for PP-PTSD in the past, were done to decrease the chance of missing women who had recovered from their earlier PP-PTSD symptoms. Significant variables in the analysis for predicting a diagnosis of or receiving treatment for PP-PTSD had a Nagelkerke

R^2 of respectively 0.086 and 0.038. Combining women with either a diagnosis of PP-PTSD by one of these professionals, or treatment for PP-PTSD, or meeting the DSM-5 symptom criteria for PTSD (B, C, D and E) at time of participation in the study led to analyses with a Nagelkerke R^2 of 0.154. Overall, the low Nagelkerke R^2 of the three analyses shows that the predictors that were used are less able to distinguish women with a history of or treatment for PP-PTSD from those without a history of or treatment for PP-PTSD than using current PTSD as the outcome variable. This makes the predictors in these three models less relevant as target points for research on prevention of PP-PTSD.

Discussion

The objective of this retrospective study was to identify antepartum vulnerability factors and predisposing factors during childbirth, for use as predictors in a predictive model for the development of PP-PTSD in women with a traumatic childbirth experience. This predictive model was made to determine the respective weight of the different factors in order to be able to develop a preventative approach. Lack of social support, low sense of coherence, experiencing 'threatened death' and experiencing 'actual or threatened injury to the baby' were the four significant contributing factors in our predictive model. The results of this study extend current knowledge of risk factors for PP-PTSD by identifying the most significant predictors for the development of PP-PTSD in women with a traumatic childbirth experience. The significant antepartum vulnerability factors in our predictive model could possibly be used as intervention points aimed at improving coping and social support, thereby either preventing the traumatic experience or mitigating its consequences.

A predictive model was constructed with an overall accuracy of 66.5% at a threshold of -1.57 and a sensitivity of 80.8% and specificity of 62.6%, based on women with symptoms of PP-PTSD. In a study by O'Donovan et al. (7), a model was constructed for predicting PP-PTSD status four to six weeks after a traumatic childbirth experience. Their model had an overall accuracy of 92.1% and a sensitivity of 52.2% and specificity of 99.2%. The overall accuracy of that model is higher than the model in our study. This can partially be explained by the fact that they investigated other variables in their study and used fourteen other predictors in their model in addition to the predictors we have investigated in our study. Also, the lower prevalence of PP-PTSD in their study population (8.5% vs. 21.5% of women meeting criteria B, C, D and E in our study) in combination with a higher specificity makes it difficult to compare both models on their level of accuracy (27).

In addition, our study found that the variables poor coping abilities, low social support, fear of childbirth, antepartum check-ups in secondary care (including referrals), a history of PTSD (due to trauma other than giving birth) or depression and meeting the DSM-5 A criterion for PTSD were significantly associated with meeting the DSM-5 criteria B, C, D and E for PP-PTSD in a univariable analysis. These variables correspond with previous studies about risk factors for PP-PTSD (5, 7, 9). Psychosocial characteristics were stronger predictors of PP-PTSD than mode of delivery or caregiver during delivery. These results confirm the earlier suggestion of O'Donovan et al. (7) that psychosocial predictors play a more prominent role in development of PP-PTSD than medical events. Also the increasing individualism in the current society makes it that pregnant women are more dependent on themselves. This will make it more interesting to focus on the effect of interventions aimed at increasing social support in pregnant women.

A remark must be made regarding the prevalence of psychiatric disease, which would ideally be compared to a reference group. Comparison with the largest nationwide study investigating the prevalence of psychiatric disorders in the Netherlands (NEMESIS-2) proved to be unreliable, because of a difference in methods used. In the current study the prevalence of psychiatric diagnoses was based on asking participating women about conditions diagnosed by psychologists, psychiatrists or general practitioners. There is no information about the way these diagnoses were made. Prevalence in the nationwide study was based on the CIDI 3.0, a questionnaire about symptoms (and not diagnosis) of different psychiatric diseases, as assessed by an interviewer (28). This could explain the higher prevalence (41.0%) of psychiatric disease in NEMESIS-2 in comparison with our study (26.3%).

Ideally, we would be able to distinguish women with a traumatic delivery experience who will develop PP-PTSD from those who will not. The closest proxy for this in this retrospective study would be to group women experiencing symptoms at the time of participation (i.e., meeting DSM-5 criteria on the PCL-5) and women with previous but not current childbirth-related PTSD (i.e., following treatment and/or a PP-PTSD diagnosis) together. This model, however, proved to be weaker than a model based solely on women with present symptoms of PP-PTSD. One reason for the predictors in our study being less able to distinguish between those two groups could be that these predictors, such as coping style, might have improved over time through treatment, or that the participants' social support deteriorated through their suffering from symptoms of PP-PTSD. However, there is no study to date reporting on changes in psychosocial functioning after treatment for PP-PTSD (13).

In addition, it is possible that more assertive women or women with a more 'objective' trauma were more likely to seek and receive treatment than women

with higher antepartum vulnerability. The latter is in line with the results of the current study, in which women who experienced threatened death were significantly more likely to get treatment than women without this experience. It could possibly be that women with a more 'objective' trauma have been taken more seriously by their mental health care providers and have been more likely to be offered treatment.

In this study it was decided to consider coping style as an antepartum factor, because it could serve as an important predictor for an antepartum predictive model and a possible target for interventions aimed at prevention, despite the postpartum role of coping in the development of PP-PTSD and the possibility of this changing during delivery and following trauma (9, 20). There is also no literature available about recent changes in coping abilities.

The reason for including the A criterion 'threat to physical integrity' from the DSM-IV in the questionnaire was based on the transition from the DSM-IV to the DSM-5 during the time period under investigation, and the hypothesis that for many women, loss of control, lack of informed consent and not being treated respectfully was crucial in their attribution of the trauma, as demonstrated in the article by Hollander et al (16). Indeed, of the 19% (65/343) of women who meet the DSM-5 criteria for PTSD (B, C, D and E) but not the DSM-5 A criterion, 40% (26/65) do meet the DSM-IV A1 trauma criterion. This warrants further reflection on the applicability of the definition of trauma to women at risk for PP-PTSD. This is particularly important, given the wide range of women who report experiencing the delivery of traumatic, which is partially dependent on the definition of trauma and how this is measured"

Strengths and limitations

There are a number of limitations to the current study design. A consequence of the retrospective design of this study is that the questionnaires can only hypothesize about the psychosocial situation before delivery, such as social support and sense of coherence. Recent studies found that sense of coherence can change during pregnancy (20, 21). In addition, recall bias could play a role in the manner that women look back on childbirth and for example the degree of fear of childbirth they experienced during pregnancy. This could lead to under- or overestimating the effect of different predictors, depending on the effect of PP-PTSD on those predictors. Another limitation is that self-reported symptoms of PP-PTSD were used in the analysis of the predictors, instead of a diagnosis based on a structured interview. Furthermore, consideration should be given to the fact that more than half of the women (54.3%) filled out the questionnaire more than two years after their traumatic childbirth experience, which may have led to missing women with PP-PTSD in remission. Finally, 26.0% of

participants declared that they recognized the symptoms from the PCL-5 from an earlier period and that those symptoms had to do with the traumatic childbirth experience. It is possible that women with severe symptoms of PP-PTSD were more likely to fill out the questionnaire, leading to an overestimation of the effect of some predictors. The analyses of women with either a diagnosis of or treatment for PP-PTSD in the past, or who currently had symptoms, were therefore done to decrease the chance of missing women who had recovered from their earlier PP-PTSD symptoms. Lastly, there could be some form of selection bias by excluding an extra 584 participants from the study for this article, because they did not complete the entire questionnaire. These excluded participants less often reported a threat to their own life, actual or threatened serious injury and a threat to their physical integrity compared to the 1599 women included in the analyses in the current article, which could have led to an overestimation of the effect of the predictors.

There are also several strengths to this study. First and foremost, it was possible to illicit a large response through an online questionnaire, which makes this study larger than any of the previous studies about the occurrence of PP-PTSD in women with a traumatic childbirth experience (7, 10). Also, the questionnaire contained four psychological measurement tools, which have been validated for measuring coping abilities, social support, fear of childbirth and symptoms of PTSD. In addition, the study population differs significantly from the general Dutch population with regard to parity at the time of the traumatic childbirth experience, age of the mother during childbirth, gestational age, ethnicity, mode of delivery and responsible caregiver during pregnancy and delivery (29, 30). These variables correspond to the risk factors known in literature, which increases the assumption that the study population is a representative group of women with a traumatic childbirth experience (7, 10). Finally, to our knowledge, this study is the first exploratory study that tried to establish predictive factors and determine their respective weight in predicting PP-PTSD according to the DSM-5 in women with a traumatic childbirth experience, thereby creating new insights into the role of antepartum vulnerability factors with regard to the development of PP-PTSD symptoms in women with a traumatic childbirth experience. These new insights could be the basis for further research into interventions aimed at preventing PP-PTSD.

Conclusion

This study identified several antepartum and intrapartum vulnerability factors in women with a self-reported traumatic childbirth experience that were predictive for the development of postpartum PTSD symptoms, corresponding with criteria B, C, D and E in the DSM-5. Four significant contributing factors predictive of developing PP-PTSD emerged from this study: lack of social support, low sense of coherence, experiencing 'threatened death' and experiencing 'actual or threatened injury to the baby'. This predictive model had an overall accuracy of 66.5%, a sensitivity of 80.8% and specificity of 62.6%. Despite the retrospective method used for this study, this predictive model demonstrates the importance of coping abilities and social support in women reporting PP-PTSD symptoms after a traumatic childbirth experience. Further research should focus on the effect of interventions during pregnancy aimed at strengthening coping skills and increasing social support in pregnant women.

References

1) Ayers S, Pickering AD. Do women get posttraumatic stress disorder as a result of childbirth? A prospective study of incidence. Birth. 2001;28(2):111-8.
2) Grekin R, O'Hara MW. Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis. Clin Psychol Rev. 2014;34(5):389-401 DOI: 10.1016/j.cpr.2014.05.003.
3) Yildiz PD, Ayers S, Phillips L. The prevalence of posttraumatic stress disorder in pregnancy and after birth: A systematic review and meta-analysis. J Affect Disord. 2017;208:634-45 DOI: 10.1016/j.jad.2016.10.009.
4) Dekel S, Stuebe C, Dishy G. Childbirth Induced Posttraumatic Stress Syndrome: A Systematic Review of Prevalence and Risk Factors. Front Psychol. 2017;8:560 DOI: 10.3389/fpsyg.2017.00560.
5) Stramrood CA, Paarlberg KM, Huis In 't Veld EM, Berger LW, Vingerhoets AJ, Schultz WC, et al. Posttraumatic stress following childbirth in homelike- and hospital settings. J Psychosom Obstet Gynaecol. 2011;32(2):88-97 DOI: 10.3109/0167482X.2011.569801.
6) Creedy DK, Shochet IM, Horsfall J. Childbirth and the development of acute trauma symptoms: incidence and contributing factors. Birth. 2000;27(2):104-11.
7) O'Donovan A, Alcorn KL, Patrick JC, Creedy DK, Dawe S, Devilly GJ. Predicting posttraumatic stress disorder after childbirth. Midwifery. 2014;30(8):935-41 DOI: 10.1016/j.midw.2014.03.011.
8) Ayers S. Delivery as a traumatic event: prevalence, risk factors, and treatment for postnatal posttraumatic stress disorder. Clin Obstet Gynecol. 2004;47(3):552-67.
9) Ayers S, Bond R, Bertullies S, Wijma K. The aetiology of post-traumatic stress following childbirth: a meta-analysis and theoretical framework. Psychol Med. 2016;46(6):1121-34 DOI: 10.1017/S0033291715002706.
10) Soet JE, Brack GA, DiIorio C. Prevalence and predictors of women's experience of psychological trauma during childbirth. Birth. 2003;30(1):36-46.
11) American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 4th ed. Washington DC 1994.
12) Dikmen-Yildiz P, Ayers S, Phillips L. Longitudinal trajectories of post-traumatic stress disorder (PTSD) after birth and associated risk factors. J Affect Disord. 2018;229:377-85 DOI: 10.1016/j.jad.2017.12.074.
13) de Graaff LF, Honig A, van Pampus MG, Stramrood CAI. Preventing Posttraumatic Stress Disorder following childbirth and traumatic birth experiences: A systematic review. Acta Obstet Gynecol Scand. 2018 DOI: 10.1111/aogs.13291.
14) CVZ, (College for Health Care Insurance). Verloskundig Vademecum. Diemen, the Netherlands 2003.
15) Survey Monkey: an Online Survey Tool [Internet]. San Mateo: Survey Monkey; [cited 2018 Jan 10]. Available from: https://nl.surveymonkey.com/.
16) Hollander MH, van Hastenberg E, van Dillen J, van Pampus MG, de Miranda E, Stramrood CAI. Preventing traumatic childbirth experiences: 2192 women's perceptions and views. Arch Womens Ment Health. 2017;20(4):515-23 DOI: 10.1007/s00737-017-0729-6.
17) American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Washington, DC 2013.
18) Weathers F.W. BDD, Schnurr P.P., Kaloupek D.G., Marx B.P., Keane T.M. The PTSD Checklist for DSM-5 (PCL-5) 2013 [Retrieved from the National Center for PTSD website]. Available from: http://www.ptsd.va.gov.
19) Antonovsky A. The structure and properties of the sense of coherence scale. Soc Sci Med. 1993;36(6):725-33.
20) Hildingsson I. Sense of coherence in pregnant and new mothers - A longitudinal study of a national cohort of Swedish speaking women. Sex Reprod Healthc. 2017;11:91-6 DOI: 10.1016/j.srhc.2016.10.001.
21) Sjostrom H, Langius-Eklof A, Hjertberg R. Well-being and sense of coherence during pregnancy. Acta Obstet Gynecol Scand. 2004;83(12):1112-8 DOI: 10.1111/j.0001-6349.2004.00153.x.

22) Boen H, Dalgard OS, Bjertness E. The importance of social support in the associations between psychological distress and somatic health problems and socio-economic factors among older adults living at home: a cross sectional study. BMC Geriatr. 2012;12:27 DOI: 10.1186/1471-2318-12-27.
23) Dalgard OS, Dowrick C, Lehtinen V, Vazquez-Barquero JL, Casey P, Wilkinson G, et al. Negative life events, social support and gender difference in depression: a multinational community survey with data from the ODIN study. Soc Psychiatry Psychiatr Epidemiol. 2006;41(6):444-51 DOI: 10.1007/s00127-006-0051-5.
24) Rouhe H, Salmela-Aro K, Halmesmaki E, Saisto T. Fear of childbirth according to parity, gestational age, and obstetric history. BJOG. 2009;116(1):67-73 DOI: 10.1111/j.1471-0528.2008.02002.x.
25) Nagelkerke NJD. A note on a General Definition of the Coefficient of Determination. Biometrika. 1991;78(3):691-2.
26) Youden WJ. Index for rating diagnostic tests. Cancer. 1950;3(1):32-5.
27) Alberg AJ, Park JW, Hager BW, Brock MV, Diener-West M. The use of "overall accuracy" to evaluate the validity of screening or diagnostic tests. J Gen Intern Med. 2004;19(5 Pt 1):460-5 DOI: 10.1111/j.1525-1497.2004.30091.x.
28) de Graaf R, ten Have M, Tulthof M, van Dorsselaer S. The psychiatric health of the Dutch population; NEMESIS-2: Design and first results. In: Addiction. TiNIoMHa, editor. Utrecht2012.
29) Perinatal care in the Netherlands 2013 [Internet]. Foundation Perinatal Registration the Netherlands. 2014.
30) CBS, (Central Bureau for Statistics). Geboorte; kerncijfers. Den Haag/ Heerlen 2017.

Part 3

Results put into practice

"A woman's relationship with her maternity providers is vitally important. Not only are these encounters the vehicle for essential lifesaving health services, but women's experiences with caregivers can empower and comfort or inflict lasting damage and emotional trauma."
White Ribbon Alliance, Respectful Maternity Care, 2011

10

Women desiring less care than recommended during childbirth: three years dedicated clinic.

Accepted, Birth
Matthijs van der Garde, Martine Hollander, Gert Olthuis,
Frank Vandenbussche and Jeroen van Dillen.

Abstract

Background
Some women decline recommended care during pregnancy and birth. This can cause friction between client and provider.

Methods
A designated outpatient clinic was started for women who decline recommended care in pregnancy. All women who attended were analyzed retrospectively. The clinic used a systematic multidisciplinary approach. During the first visit, women told their stories and explained the reasoning behind their birth plan. The second visit was used to present the evidence underpinning recommendations and attempt to reach a compromise if care within recommendations was still not acceptable to the woman. During the third visit, a final birth plan was decided on.

Results
From January 1st 2015 until December 31st 2017, 55 women were seen in the clinic, 29 of whom declined items of recommended care during birth and were included in the study. After discussions had been completed, 38% of birth plans were within recommendations, 38% were a compromise, in which both the woman and the care provider had made certain concessions, and 24% did not reach an agreement and delivered with another provider either at home or elsewhere. All maternal and perinatal outcomes were good.

Conclusions
Using a respectful and systematic multidisciplinary approach, in which women feel heard and are invited to explain their motivations for their birth plans, we are able to arrive at a plan either compatible with or much closer to recommendations than the woman's initial intentions in the greater majority of cases, thereby preventing negative choices.

Background

In 2013, three Dutch midwives faced disciplinary action from the medical review board. They were accused of stepping outside their mandate and overestimating their expertise, by assisting four women during home births in high risk pregnancies. The cases involved twins and breech births.[1]

The actions of these midwives were unusual, since the Netherlands has a two-tiered system of maternity care. Low risk women are under the care of community midwives, and have the option of giving birth at home, in a birthing centre or in a hospital with their own midwife, whereas high risk women or those who become so, such as twins and breech births, are cared for in hospitals by obstetricians, trainees and clinical midwives.

The verdict of the review board was for all midwives to be reprimanded, and for one of them to permanently lose her license. This verdict was overturned on appeal, where the board of appeals reasoned that these midwives were delivering 'second best care', since, if they had withdrawn care, their clients might have felt they had no other choice but to give birth at home unassisted[2].

In the wake of these cases a debate arose among Dutch maternity care professionals concerning how best to approach conversations with women who decline recommended care. A multidisciplinary national guideline on how to discuss requests for less care than recommended was written and implemented.[3] The main message of this guideline is that a maternity care provider is responsible for a correct procedure and appropriate advice, but is not accountable for the (adverse) consequences of decisions made by a competent client.

In spite of the new guideline, many professionals were still unsure how best to counsel women who declined their advice. In 2013 the Amsterdam University Medical Center started a designated outpatient clinic[4] with the aim of increasing expertise and improving care for these women, who, as reported in a recent paper by Holten et al.[5], frequently encountered conflict elsewhere. The Radboud University Medical Center in Nijmegen followed their lead and opened a similar clinic in January of 2015.

In this article we retrospectively analyze and report the experience of the first three years of this clinic: January 2015 - December 2017. The main purpose of this study was to give an overview of the women seen in our dedicated clinic and outline our approach. In addition, we were interested in the percentage of cases in which we were able to reach an agreement with the woman about the birth plan, how many women were seen, what particular care they declined, in which percentage of cases it was possible to arrive at a birth plan that was within recommendations, in which percentage of cases a consensus management plan (birth plan partially outside recommendations) was reached, and what the outcome was of all these pregnancies.

Methods

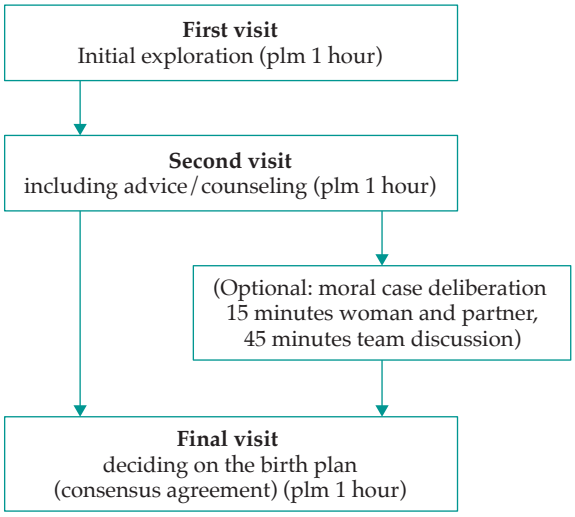
The designated outpatient clinic 'Maternity Care Outside Guidelines' is run by two obstetricians with an affinity for this subject matter (MH and JvD). Women are referred by primary care midwives from the community, in-house by colleagues, or by hospital staff elsewhere. Women are seen at the clinic a minimum of three times. The community midwife involved in the case is encouraged to be present for all clinic visits. Visits are structured according to a predetermined plan (Figure 1), but are flexible, since no two 'cases' are identical. The first visit lasts approximately one hour and is reserved exclusively for listening to the woman's plans and ideas for the upcoming birth, and determining what motivates certain refusals or requests. Since previous trauma has been shown to be an important part of women's reasons for wanting to deviate from advice[6], much time is spent exploring past obstetrical history, with emphasis on how women feel about these births in hindsight, and how those feelings influence the current plans and ideas. We also try to determine the extent of the woman's understanding of relevant risks and chances, without countering these cognitions with our own interpretation of the evidence.

During the second visit, if the provider is convinced that enough trust has been earned for the woman to feel that she wants to hear our advice, the relevant guidelines are discussed. In this conversation, the evidence (and also sometimes lack of evidence) behind these recommendations is presented in a non-threatening way. The aim is to inform, not to frighten her into consenting to adhere to protocol. Risks and chances are presented with actual numbers and percentages, not odds ratios, and both numbers needed to treat and numbers needed to harm are used. In addition, evidence levels are discussed, with more emphasis being placed on evidence level A and B than on recommendations through professional consensus. During these visits, the steps in the guideline 'Maternity care outside guidelines' are followed.

Finally, in the last visit, solutions are explored. If the woman still wishes to deviate from recommendations, alternative solutions are discussed. These can consist of a medical birth with fewer interventions than recommended, a hospital birth with a community midwife, or a home birth with a community midwife. The purpose throughout the entire process is to find a solution that is acceptable to the woman, with the minimum risk for her and her child.

If an agreement is reached which is deemed a challenge for the maternity department team, a 'moral case deliberation' is called[6]. This meeting is chaired by a member of the hospital ethics staff, and all maternity care team members, including the community midwife, are invited. The woman (and her partner) are invited to present their wishes to the team, and answer a few questions.

Figure 1 Structure of visits



Then the team continues the meeting behind closed doors, where all team members can discuss their feelings about the plan. In these discussions, the autonomous preferences of the woman (and partner) are weighed against the professional responsibilities of the maternity team. However, the team is legally obliged to respect the woman's refusal, except when an alternative hospital can be found that is comfortable with the birth plan. In very rare cases, when several team members are very uncomfortable with the plan, the two obstetricians who run the clinic may offer to be on call for a particular birth.

Women who visited the designated clinic were recorded in a database. All women who had a first visit between January 2015 and December 2017 were included in this study. Initial reason for referral, final consensus within or outside recommendations, 'moral case deliberation', and pregnancy outcomes were extracted from patient files. A distinction was made between requests for more care than recommended, declining recommended care, and requests for different care than usual. Only declining recommended care is the subject of this article, and was further analyzed. This study was deemed to be exempt from ethical approval by the medical ethics committee of the university of Nijmegen, the Netherlands.

Results

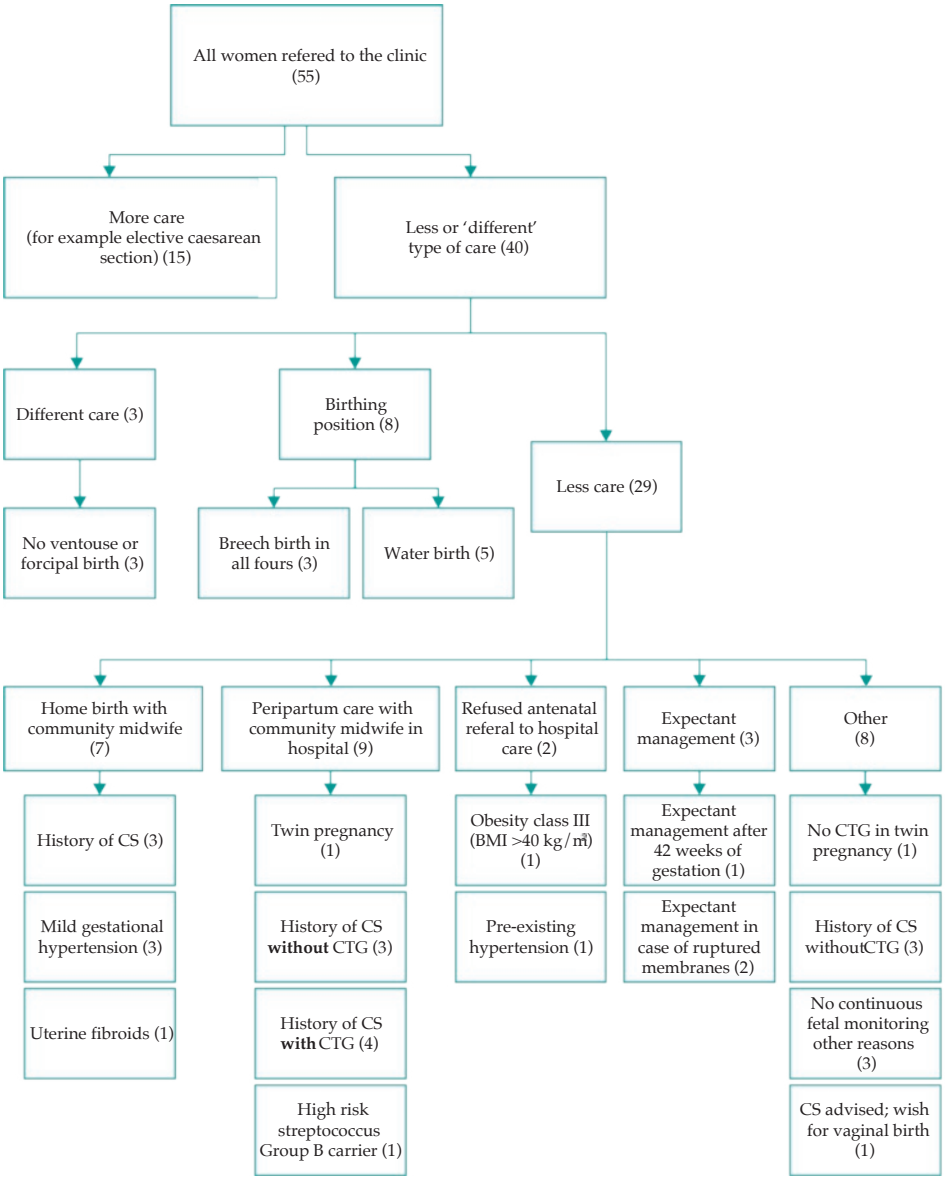
Between January 1st 2015 and December 31st 2017, 55 women had a first visit in the designated clinic. Most of the women who visited the clinic were referred by midwives in our own catchment area of (city) and the surrounding communities. Fifteen women had a request for more care than medically necessary (for instance elective caesarean section) and were excluded from further analysis. Another eleven women requested different care than usual. These cases included a preference for caesarean section as opposed to an assisted vaginal birth in the event of failure to progress during the second stage, a preference for upright (all fours) position during breech birth, or a desire to have a water birth, which was not possible in this hospital until January 2018. None of these requests are against medical advice per se, however, they may fall outside the comfort zone of some maternity care providers. The remaining 29 women desired less care than recommended during pregnancy and childbirth and were therefore selected for further analysis (Figure 2).

Most of the women who desired less care than recommended had experienced a previous trauma, undermining their trust in medical professionals. Their motivations to decline recommended care aligned with those of the women in our previous qualitative study, including disagreement about what constituted "superior knowledge", a need for autonomy and trust in the natural birth process, a conflict (elsewhere) in the negotiation of their birth plan, and a search for the type of care that they wanted.[7]

Medical reasons for recommending hospital birth under supervision of an obstetrician are outlined in the Dutch national multidisciplinary list of recommendations ('the VIL').

Two women had a pre-existing medical condition (one morbid obesity (Body Mass Index >40), one pre-existing hypertension) and declined to be referred by their community midwife for secondary (hospital) care during pregnancy. Seven women had a medical reason for giving birth under supervision of an obstetrician, but desired a home birth: three had had a previous caesarean section, three had developed mild hypertension at term, and one had uterine fibroids. Three women wanted to postpone an indicated induction of labor: one for being overdue (>42 weeks), and two for ruptured membranes longer than the recommended 24 hours. Nine women had a medical reason for giving birth in hospital under supervision of an obstetrician, but were only willing to come in if their community midwife was allowed to supervise the birth: one twin pregnancy, one a streptococcus Group B carrier who had an indication for antibiotic treatment during the birth and seven who had had a previous caesarean section, four of whom were willing to accept continuous fetal

Figure 2 All women referred to the designated clinic



CS = caesarean section; CTG = cardiotocography; BMI = body mass index

monitoring, and three who would only accept intermittent auscultation. Finally, there were eight women who declined other recommended interventions. These included one woman with a twin pregnancy who declined any fetal monitoring, routine pelvic exams, or intravenous access and insisted on birthing both babies on all fours, one woman who declined a recommended caesarean section for a previous fatal shoulder dystocia and insisted on a vaginal birth, three women with previous caesarean sections who declined continuous fetal monitoring and routine pelvic exams, and three women with other indications for continuous fetal monitoring who declined this intervention.

Of these 29 women, eleven eventually accepted all recommended care (11/29, 38%), with eleven women (38%) an adapted birth plan (consensus management plan) was agreed on, and seven women (24%) continued to decline recommended care (Figure 3). Of these seven women, three women with previous caesarean sections and three with mild hypertension at term gave birth at home with a midwife against medical advice, and one woman with twins decided to refer herself to another hospital, because she did not want to attend a 'moral case deliberation'. Of the eleven women with whom a consensus management plan was agreed on, one woman was referred back to her original hospital, where our plan was adopted. All others gave birth in our unit.

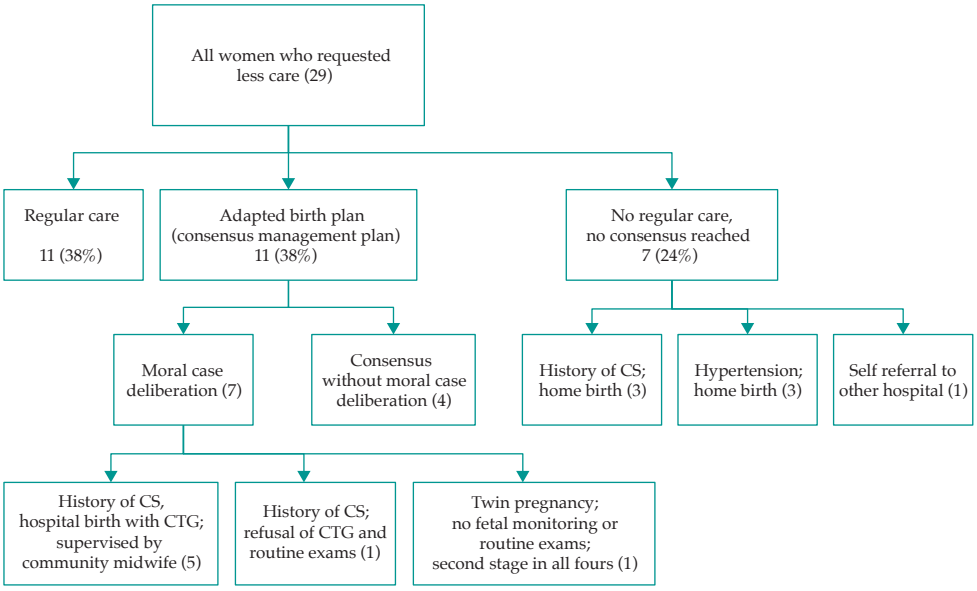
After visiting the designated clinic, seven consensus management plans warranted a 'moral case deliberation': five women with previous caesarean sections who wanted their own community midwife to catch the baby, but accepted a hospital birth with continuous fetal monitoring, one woman with a twin pregnancy who declined any fetal monitoring, routine pelvic exams, or intravenous access and insisted on birthing both babies on all fours, and one woman who declined continuous fetal monitoring, intravenous access and routine pelvic exams during a trial of labor, whose case is described here as an example.

This woman presented at the clinic with her community midwife. She had had a previous caesarean section elsewhere due to breech position, which she felt had been forced on her with no option of a vaginal breech birth. During this current pregnancy, she had become resolved to give birth at home with her community midwife, because she had lost trust in hospital staff and wanted to retain her autonomy. Her community midwife, however, did not feel comfortable with a home vaginal birth after caesarean (VBAC) and suggested visiting our clinic together. At the first visit, the woman expressed a willingness to give birth in the hospital, but only if her community midwife managed the labor and caught the baby. She refused all fetal monitoring except intermittent (doptone) auscultation and would only allow vaginal examinations at her own request. She refused intravenous (IV) access. The initial visit consisted of listening to her grievances and wishes for the

imminent birth. During the second visit, current guidelines pertaining to VBAC were discussed, together with the evidence underpinning recommendations for continuous fetal monitoring, regular monitoring of progress, and IV access. At the end of this visit, a compromise was reached, where she would give birth in the hospital, with hospital staff in attendance, with IV access and intermittent monitoring by cardiotocography. She was willing to allow pelvic exams once every four hours at minimum, more if she felt comfortable. The woman made it very clear that this was as far as she was willing to go, and that if the plan was not approved she would stay at home and call on her community midwife, who would be legally obliged to attend. The case was presented for moral case deliberation, and the plan was accepted based on the second best principle.

All plans were eventually accepted by the team, many because the alternative would have meant a home birth in a high risk pregnancy or an unassisted childbirth. In one instance, levels of discomfort among staff were so high that one of the obstetricians from the designated clinic offered to attend the birth. All perinatal and maternal outcomes were good. There were no perinatal deaths, no neonatal intensive care unit admissions, and no severe maternal morbidity.

Figure 3 Final outcome after attending the designated clinic



CS = caesarean section; CTG = cardiotocography

Discussion

This study reports on the structure and results of the first three years of a designated clinic for women who desire less care than recommended during pregnancy and childbirth. In that time, 55 women were seen for a first visit, 26 of whom desired more, or just different care, while the remaining 29 desired less care than recommended by protocols and guidelines. More than a third of these 29 women eventually decided on a management plan that was compatible with recommendations, more than another third reached a consensus outside recommendations, albeit usually less than they originally intended, and a quarter could not reach consensus and gave birth with a midwife at home or in a hospital elsewhere.

There appears to be a paucity of literature concerning other designated clinics for this subject worldwide. However, there is ample recent literature on the motivations of women who choose to go against medical advice in their birth wishes and opt for a home birth in a high risk pregnancy or even an unassisted childbirth.[8-13] Many of these women have had a previous traumatic childbirth experience.[10,14-16] An important cause of this trauma reported by women is lack or loss of control, interventions being performed routinely without informed consent, and lack of support and communication by maternity care professionals.[17] These experiences prompt women to decide that they want the next time to be different. Some women make extensive birth plans, to protect themselves from having this trauma repeated. Recent studies concerning birth plans and women's satisfaction show that, despite women with a birth plan undergoing less interventions, they are still less content with the care they received than women without a birth plan.[17,18] This may be due to higher expectations, or to professionals experiencing an aversion to extensive birth plans.[19]

Another possible reason for the mismatch between women's desires and professionals' recommendations, is the gradual shift in patient agency. Women are encouraged to take responsibility for their own health, write a birth plan and find a suitable professional. This concerns a relatively young group of patients, with access to social media, who are encouraged to develop their own views on how they want to give birth. However, they are confronted with a growing number of professional guidelines, explained to them by care providers with an increasing fear of litigation, who are at the same time encouraged to practice shared decision making.[20] In addition, recommendations in pregnancy are not a black and white matter, and are not consistent over time. However, this relativity may sometimes be lost in translating a guideline into recommendations to a pregnant woman. Recommendations in guidelines are based on small chances

of serious pathology. How to interpret this evidence in light of personal preferences requires strong provider skills and an excellent working relationship between woman and professional.

It seems more and more difficult for professionals to deviate from protocols, which are often treated as firmer evidence than they are. As providers, we are used to thinking in odds ratios, whereas for the average patient, exact numbers (1 in 100) or percentages (1% or 99%) are more understandable. Perception of risk between provider and woman may differ, such that a 0.5% chance of uterine rupture, for a provider, is sufficient reason to justify a monitored hospital birth, whereas for the woman, a 99.5% chance of no rupture may feel safe enough for a home birth, especially if the previous caesarean section was a traumatic experience.[21] It is therefore of the utmost importance to discuss why women decline recommended care. If an agreement is to be reached, this will only happen if both parties explain their reasoning. For example, a request for a home birth after a previous caesarean could originate in the desire to give birth in a familiar environment with the community midwife, or it could be declining continuous fetal monitoring due to fear of excessive intervention rates.

All these factors may contribute to the increase in requests for maternity care outside protocols and guidelines. Of the 29 women that were seen in the designated clinic declining recommended care, we were unable to reach an agreement with 24%, where previously this percentage would have been much higher. In all other cases, the final consensus was either fully within recommendations, or was a compromise between the recommended management plan and the woman's original wishes. We believe this is due to the specific approach of this clinic. It is possible that, if not for visiting our clinic, many if not most of these women would have given birth at home, or they would have presented during labor with a birth plan declining many items that were not previously discussed. It seems unlikely that, in the heat of the moment, there would have been much room left for discussion or consensus. In addition, some of the women who visited our clinic might have called on their community midwife during labor, even if the community midwife was not in agreement with their plan for a home birth. Involving the community midwife in our clinic ensured that not only were they completely informed about what was discussed and what the final plan entailed, but they were also able to be part of the consensus plan, as in the cases of women who only agreed to give birth in hospital if their own midwife attended. There were a few cases where women were already decided on having a home birth in a high risk pregnancy, and nothing we could offer could convince them otherwise. In those cases, too, the clinic was helpful. A chart was made documenting the woman's plans and ideas, so that, in case of things not going according to plan at home, there would be a record of the

woman's intentions and what had been discussed. This would prevent uncomfortable situations during referral for both the woman and her midwife.

In summary, this designated clinic, by virtue of its systematic multidisciplinary approach, fulfills a need that might otherwise go unmet. We believe that, by following a step-by-step approach, using the method of counseling described above, and by putting ourselves next to the woman instead of opposite, many birth plans ended up being much less against recommendations than they might otherwise have been. This could prevent women from having a home birth in a high risk pregnancy or an unassisted childbirth, only because the community midwife or hospital was unwilling to consider a compromise.

However, we also believe that women travelling outside their own region to attend a designated clinic such as ours, is not desirable. Ideally, we would prefer women to have these discussions with their own providers. The steps described in this article are not that different from the steps of shared decision making[22], which has been incorporated in many recent guidelines as the new standard of care in provider-client interaction. Therefore, we hope that, in future, women will be able to discuss birth plans that differ from recommendations with their own maternity care provider, and that all providers will see these conversations not as a nuisance or a denial of their expertise[23], but as a chance to reach an agreement where otherwise there might have been none.

Strengths and limitations

The main strength of this study is that it is the first to describe the structure and results of a clinic designated to serve women who desire less care than recommended during pregnancy and childbirth. This knowledge could be useful for other hospitals and midwifery practices who are struggling to meet the needs of women while maintaining safety, without 'losing' their client altogether. A second strength is that this study presents a complete record of the first three years of this clinic, with no drop-outs or loss of follow-up. Finally, this clinic ran concurrently with the Wonder-study (www.wonderstudie.nl), which examines the reasons women and their partners have for wishing to deviate from advice, the motivations of their holistic midwives to assist them, and the experiences of Dutch midwives and obstetricians with this issue. The knowledge gained from this study has helped the team running this clinic in learning how best to approach these conversations.

Naturally, there are also some limitations to this study. First, no other clinics like this one have been described, therefore we cannot compare our approach and results to those elsewhere. Second, there is no control group, which means that it is impossible to prove that the outcomes of our approach are any better than would be achieved in standard care, even if there were agreement on what

parameters would be used. Finally, due to the wide diversity in cases seen in this clinic, our flow chart was not always strictly followed, since some conversations needed more time to come to an agreement.. However, we do believe that, by letting the woman set the agenda, we were able to reach a point in which the woman wanted to hear our recommendations in almost all cases.

Conclusions

This study describes the structure and results of the first three years of a designated clinic for women who decline certain items of recommended maternity care in their birth plans. We found that, through listening and counseling in a respectful manner using a structured multidisciplinary approach, we were able to either reach a compromise that was acceptable to all parties, or end up completely inside protocol, in the majority of cases. The designated clinic was useful in negotiating procedures which often resulted in risk reduction for the individual woman. Also, the careful negotiation and documentation during this process helped smooth relations between obstetricians and community midwives, and to provide some protection for midwives tasked with continuing to care for these women, sometimes under difficult circumstances. All maternal and perinatal outcomes were good.

We hope that the results from this study will help all maternity care providers in carrying out these conversations with their own clients, so that in the near future there will be no more need for a designated clinic of this type, and all pregnant women, whatever their birth plans, will find that they can discuss their wishes with their own providers.

References

1. Government news site. Verdict of Regional Disciplinary Board. 2012. Retrieved from http://tuchtrecht.overheid.nl/ECLI_NL_TGZRAMS_2013_14 (accessed 7-8-2018)
2. State Newspaper. Verdict of Central Disciplinary Board. 2014. Retrieved from https://zoek.officielebekendmakingen.nl/stcrt-2014-18656.html (accessed 7-8-2018)
3. NVOG and KNOV. Guideline on maternity care outside guidelines. 2015. Retrieved from https://www.nvog.nl/wp-content/uploads/2018/02/Leidraad-Verloskundige-zorg-buiten-richtlijnen-1.0-30-11-2015.pdf (accessed 7-8-2018)
4. Amsterdam University Medical Center. Website of the clinic for designated maternity care (POM). 2012. Retrieved from https://www.amc.nl/web/ik-heb-een-afspraak-1/mijn-afspraak-in-het-amc/poli-ondersteuning-maatwerk-zwangerschap-geboorte-pom-polikliniek.htm (accessed 7-8-2018)
5. Holten L, Hollander M, de Miranda E. When the hospital is no longer an option: a multiple case study of defining moments for women choosing home births in high-risk pregnancies in the Netherlands. *Qual. Health Res.* 2018. Oct;28(12):1883-1896.
6. Haan M, van Gurp J, Naber S, Groenewoud A. Impact of moral case deliberation in healthcare settings: a literature review. *BMC Med Ethics.* 2018 Nov 6;19(1):85.
7. Hollander M, de Miranda E, van Dillen J, de Graaf I, Vandenbussche F, Holten L. Women's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis. *BMC Pregnancy Childbirth.* 2017 Dec 16;17(1):423.
8. Viisainen K. Negotiating control and meaning: home birth as a self-constructed choice in Finland. *Soc Sci Med.* 2001 Apr;52(7):1109-21.
9. Cheyney, M. Home birth as systems-challenging praxis: knowledge, power, and intimacy in the birth place. *Qual Health Res.* 2008: 18,254–267.
10. Boucher, D, Bennett,C, McFarlin, B, Freeze, R. Staying home to give birth: Why women in the United States choose home birth. *J Midwifery Womens Health.* 2009: 54,119–126.
11. Murray-Davis, B, McNiven, P, McDonald, H, Malott, A, Elarar, L, Hutton, E. Why home birth? A qualitative study exploring women's decision making about place of birth in two Canadian provinces. *Midwifery.* 2012:28,576–581.
12. Miller, A. Midwife to myself: Birth narratives among women choosing unassisted homebirth. *Soc. Inquiry.* 2009:79,51–74
13. Holten L, de Miranda E. Women's motivations for having unassisted childbirth or high-risk homebirth: An exploration of the literature on 'birthing outside the system'. *Midwifery.* 2016 Jul;38:55-62
14. Freeze, R. Born free: Unassisted childbirth in North America (Thesis). University of Iowa. 2008. Retrieved from https://ir.uiowa.edu/cgi/viewcontent.cgi?article=1387&context=etd accessed 7-8-2018
15. Lundgren, I. Women's experiences of giving birth and making decisions whether to give birth at home when professional care at home is not an option in public healthcare. *Sex Reprod Healthcare* 2010:1, 61–66.
16. Hollander MH, van Hastenberg E, van Dillen J, van Pampus MG, de Miranda E, Stramrood CAI. Preventing traumatic childbirth experiences: 2192 women's perceptions and views. *Arch Womens Ment Health.* 2017 Aug;20(4):515-523.
17. Mei JY, Afshar Y, Gregory KD, Kilpatrick SJ, Esakoff TF. Birth Plans: What Matters for Birth Experience Satisfaction. Birth. 2016 Jun;43(2):144-50.
18. Afshar Y, Mei JY, Gregory KD, Kilpatrick SJ, Esakoff TF. Birth plans-Impact on mode of birth, obstetrical interventions, and birth experience satisfaction: A prospective cohort study. Birth. 2018 Mar;45(1):43-49.
19. DeBaets AM. From birth plan to birth partnership: enhancing communication in childbirth. *Am J Obstet Gynecol.* 2017 Jan;216(1):31.e1-31.e4.
20. Megregian M, Nieuwenhuijze M. Choosing to Decline: Finding Common Ground through the Perspective of Shared Decision Making. J Midwifery Womens Health. 2018 May;63(3):340-346.

21. Van Wagner V. Risk talk: Using evidence without increasing fear. *Midwifery*. 2016 Jul;38:21-8.
22. SHARE approach: https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-1/index.html (accessed 7-8-2018)
23. Diamond-Brown L. "It can be challenging, it can be scary, it can be gratifying": Obstetricians' narratives of negotiating patient choice, clinical experience, and standards of care in decision-making. Soc Sci Med. 2018 May;205:48-54.

11

General discussion and conclusions

A year later, Jeske is pregnant again. This time she is resolved to do things differently. She reads books about natural childbirth and joins several social media groups. She wants to have a home birth and discusses this with her midwifery practice. They advise against it because of her previous cesarean section, but arrange for Jeske to speak to an obstetrician, in a different hospital this time. The conversation goes well. Jeske is open to discussing a hospital birth, but does not want fetal monitoring. She wants to deliver with her own midwife, and have a water birth. Most of all, she wants to stay in control and be left alone during labor. Even though the obstetrician is willing to meet her halfway, and will allow for all of her wishes except no fetal monitoring, Jeske decides to pursue a home birth. She feels that the risk of unnecessary interventions due to false positive fetal monitoring readings, during which she will again lose her autonomy, far outweighs the risk of complications due to uterine rupture. This means that, in the third trimester of her pregnancy, she has to find another midwife to assist her. After several weeks of frantic phone calls, she finds a midwife about an hour away, who agrees to be by her side.

Jeske has 'a glorious water birth at home, with confidence and trust'. She feels that, as opposed to her first labor, she did this one by herself. Even the fact that she has to go to the hospital in the end for a manual removal of the placenta does not bother her in the least.

General discussion

Back to our initial questions…

1) What is the legal position of women who decline certain items of medical care during pregnancy and childbirth, in the Netherlands and elsewhere? What are ethical considerations? Are there limits to autonomy and how does the unborn child factor in to all of this?

Competent adults are entitled to autonomy and have a right to have their physical integrity protected. This right is undiminished if the adult is a pregnant woman. This means that nothing may be physically done to a competent adult, including pregnant women, without their consent. Medical procedures are no exception to this rule. In abortion law, children are endowed with an increasing moral right to have their life protected. Legally, they have no independent rights until the actual moment of birth, although, in most countries, after reaching viability, they can't be aborted in the absence of either a (near) fatal prognosis for themselves or serious danger to the woman. The longer the gestational age, the more worthy of protection the fetus is. However, even if a medical professional would be willing to override a competent woman's refusal of a medical procedure for the benefit of her fetus, he or she would still have to disregard the legal rights of one in order to ensure the moral rights of the other. All professional organizations who have released a guideline or opinion statement on the matter

of coercion or compulsion are in agreement that it is undesirable to override a competent pregnant woman's refusal of a medical procedure, which should therefore not be attempted.

An important underlying distinction is the difference between requests and refusals. Medical professionals have their professional autonomy, which means they are allowed to refuse requests made of them that do not align with their own values. For instance, a medical professional is allowed to refuse to perform a termination of pregnancy, when their conscience does not allow them to participate. They are, of course, ethically required to refer the woman to a colleague they believe might agree with the request. However, when it is the woman who refuses a certain intervention on her own body, the professional is not allowed to override her decision, while at the same time he or she is still ethically (and legally) bound to deliver the best possible care under the given circumstances, unless a timely referral to a colleague who feels more comfortable with the woman's refusal can be effectuated. For the women in this thesis, this means that they have the legal right to refuse any and all advised medical interventions during birth, while at the same time they can't force a maternity care provider to perform an elective cesarean section.

In cases of disagreement between pregnant woman and maternity care provider, counseling women and their partners with respect for their individual circumstances, background, opinions and convictions, and being open and honest about (absolute) risks, benefits and uncertainty, will in most cases be sufficient to reach a compromise. According to Dutch law, if a compromise can't be reached, the autonomy of the woman should prevail. This is not the case in other countries, where court ordered cesarean sections are, although perhaps rare, not unheard of. In 2015, a group of Dutch judges and obstetricians made a suggestion in the Dutch Lawyer's Journal (Nederlands Juristen Blad) to institute an 'Actio Caesarea', and make court ordered cesareans a legal possibility in the Netherlands[15]. This suggestion met with much opposition from the field, including both the NVOG and the KNOV and has thus far not yielded any legal changes.

15 https://www.njb.nl/blog/een-nieuw-ontdekte-procedure-actio-caesarea.18540.lynkx

2) What are the motives underlying the choice of some medium or high risk pregnant women to deliver at home? What are the motives underlying the choice of some women for an unassisted birth? What is the impact of 'outside the system' requests on Dutch midwives and obstetricians?

Women interviewed for the WONDER-study comprised both women who opted for a home birth in a high risk pregnancy, and women who chose unassisted childbirth (UC). Although not identical, their motivations were quite similar. Most women who were interviewed did not start out in their first pregnancy with a strong desire to have a home birth, even if the pregnancy became high risk. At some point during the (usually) first pregnancy or birth, they were traumatized, and blamed 'the system' or medical professionals for their trauma. Women described encountering a lack of continuity, flexibility, respect and shared decision making in regular maternity care, and told stories of paternalism, when instead they needed trust, autonomy and respect. Consequently, they decided to educate themselves through books, internet and social media, and devised a birth plan which was aimed at protecting them from a repeat of the trauma and helping them keep their autonomy. For the majority, this birth plan did not align with medical recommendations, which led to a conflict with their care providers. The final result was a home birth in a high risk pregnancy or a UC.

Their partners described being convinced by the women's arguments of the benefits of a home birth in a high risk pregnancy or a UC, and were committed to help their wives/girlfriends to achieve the birth they wanted.

'Holistic' midwives are relatively new in the landscape of Dutch maternity care. There is no set international definition of what a holistic midwife is, but for the purposes of this thesis they have been defined as midwives who frequently work as case-load midwives. Their view on maternity care centers around their client's wishes, rather than what protocols and guidelines recommend. They are often willing to honor requests for care that do not align with protocols or guidelines. It may not be too much of a stretch to say that they came to practice the way they do due to there being a demand for their care. Most holistic midwives work alone in case-load practice, although some are back-up to each other or share some on-calls. They distinguish themselves from other professionals by putting their client's wishes and requests first, without worrying about what protocols and guidelines say, and deliver an important service, because in many cases they are the last resort before women choose to give birth unattended by any medical professional.

Regular maternity care professionals are frequently baffled by the choices women in this thesis make. While some can understand the reasoning behind these choices, even though they do not support them, many do not understand why anyone would choose, in their view, to take risks with their own and their

child(-ren)'s health, and not follow advice they consider as the safer choice. In addition, they fear both legal and/or emotional consequences for themselves, when they are forced to deliver what is, in their eyes, substandard care, especially if the outcome is unfavorable.

3) How often do Dutch obstetric and midwifery care givers receive requests for care against medical advice and guideline/protocol? What is the attitude of these professionals delivering obstetrical care towards women who wish to give birth 'outside the system'?

When we surveyed Dutch maternity care professionals about their experience with 'outside the system', birth care requests, most respondents replied that they encountered at least one such case per year. Respondents were almost evenly divided between judging that there is an increase in request for care outside guidelines (less or more) and that there is not. However, we were able to determine that most maternity care providers receive an approximately equal number of requests for less care than for more care per year, whereas their attitude to these was very different. Providers were more willing to honor a request for more care than less care, and many community midwives referred women declining items of care in their birth plans to either a hospital or a holistic colleague, proving that many providers are distinctly uncomfortable with women declining recommended care.

Despite our best efforts, it is currently still unknown how often women choose to go against medical advice in choosing place of birth, or how often UC occurs in the Netherlands. The estimate 'in the field' is that approximately 200 UC's take place annually in this country[16]. All births are registered at town hall, and these data are then passed on to the Central Bureau of Statistics (CBS)[17]. However, since 'birth attendant' is not a required field when registering a birth at town hall, nobody knows for certain how many (intended and unintended) UC's take place each year. Home birth or hospital birth with a community ('holistic') midwife in a high risk pregnancy is also something that is difficult to quantify. Community midwives can't list all high risk pregnancy indications on their primary care forms, therefore it will frequently be unknown that this was a high risk birth. An added difficulty is that, although the Netherlands has a voluntary national registry of all births (PERINED)[18], for which maternity care professionals supply data, many holistic midwives do not participate in this national registry. The coverage of the registry is 98% of all births in the Netherlands, thus missing 2% of the births compared to CBS. Hence, there is

16 Verbeek A. Baren buiten het boekje. Tijdschrift voor Verloskundigen 2013;2013:40–4.
17 www.cbs.nl
18 www.perined.nl

currently no way to estimate how many home births in high risk pregnancies take place in the Netherlands each year.

4) What causes women to experience childbirth as traumatic? Is there anything we, as maternity care providers, could have done differently during the birth to prevent this? Is there something the women themselves would have done differently in hindsight? What are risk factors for a traumatic birth experience? Is there anything we can do during pregnancy to prepare women better for giving birth, or to identify which women are particularly vulnerable?

Women themselves attribute their traumatic birth experiences not to certain obstetrical events, or even to certain interventions, but instead pinpoint a lack or loss of control, insufficient communication and not enough emotional and practical support. This means that they are traumatized not by the fact that the ventouse extraction, the emergency cesarean section or the hemorrhage takes place, but that they aren't prepared for it and don't receive adequate explanation about what is happening and why. Interaction around interventions, therefore, seems to be more important than the interventions themselves. In addition, women don't feel that there is much they can do themselves to prevent the trauma, except asking for certain interventions sooner, or refusing them, in short, being more assertive. The largest proportion of traumatized women in our study are those who are transferred from primary care to secondary care during birth. Continuity of care and/or carer therefore also seems to be a risk factor. Another risk factor in this study was a real or perceived threat to their baby's life or health. As maternity care professionals, these are all valuable points we can use to improve our care.

Women who have little social support and lack coping skills are at increased risk of experiencing childbirth as traumatic, especially if they are transferred during birth, or encounter an event in which they fear for a (either real of perceived) threat to their baby's life or health. Identifying women at risk, particularly if they also have a complicated pregnancy, and developing tailored care to reduce this risk may be a helpful preventative strategy.

5) Finally, we wanted to evaluate what kind of requests against medical advice we had encountered at our designated clinic. What were the maternal and perinatal outcomes, and in how many cases had we been able to reach a compromise with our patients? How many cases had ended up inside protocol, and how many had chosen to disregard our advice and deliver elsewhere?

In three years running an outpatient clinic dedicated to discussing birth plans with women who decline (parts of) recommended care, we encountered a wide variety of refusals and requests. Even though counseling women desiring less care was our aim, we also saw several women who wanted more, or sometimes actually just different care than their providers were comfortable with. Some requests concerned birthing positions or water births, several were elective cesarean sections. Of the women desiring less care, about half wanted a community midwife to assist during the birth (either at home or in the hospital), in spite of it being a high risk pregnancy. The other half refused hospital care altogether, or accepted medical care, but refused certain items such as induction of labor or fetal monitoring. We found that, through a structured multidisciplinary approach, we were able to reach a consensus with more than three quarters of the women we saw, half of whom ended up completely within protocol, and the other half reached a compromise. One in four women still delivered at home, which they were often already determined to do before the first visit. All outcomes were good, which means we had no perinatal deaths or NICU admissions, and no severe maternal outcomes. We found these results reassuring, in the sense that we were able to reach a compromise with most women that was (much) closer to recommended care than their initial plans. These results should encourage all maternity care providers to attempt, through open en honest counseling, and actual shared decision making, to negotiate with their own clients, making this dedicated clinic superfluous in future.

Implications for practice

Primary prevention: preventing traumatic childbirth experiences

The studies in this thesis suggest an association between a traumatic experience (either during pregnancy or birth) and women declining recommended care for their (next) birth. Preventing the original trauma, therefore, might prevent many 'difficult' (in the eyes of the provider) birth plans.

One of the risk factors for a traumatic experience in our study seems to be transfer of care. In the Netherlands, 23% of women are transferred during labor from primary care by a community midwife to secondary (hospital) care by a

clinical midwife or a (resident) gynecologist (Chapter 8). This percentage was almost doubled (43%) in the group of women who responded to our call and had experienced childbirth as traumatic. This is consistent with findings in other studies[19,20]. When a woman is transferred during labor, it is usual for the community midwife to leave at some time after hand-over, unless the birth is imminent. Women are then left in the care of a new team whom they have never met, at a time when things are obviously not going according to plan and they are at increased risk of needing an intervention as well. They have had no time to build a relationship of trust with this team. This may well be a crucial factor in the reason why women blame their traumatic experience on factors of communication, support and explanation.

It is also as yet unclear whether the continuity that these women are missing is continuity of care or continuity of caregiver. There are some studies which indicate that women do not mind being handed over to a new team, as long as there is continuity of care and information, and the policy agreed on in the birth plan is still followed[21]. However, there are growing indications that continuity of caregiver is actually very important for women's satisfaction with childbirth[22,23,24,25]. In addition, many women in Chapter 3, and their midwives in Chapter 4, attached a great deal of importance to continuity of caregiver. One explanation for this could be, that some (traumatized) women no longer trusted in continuity of care, and therefore put their faith in one caregiver, whose presence, in their mind, would protect them against deviations from their wishes.

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19 Rijnders M, Baston H, Schönbeck Y, van der Pal K, Prins M, Green J et al. Perinatal factors related to negative or positive recall of birth experience in women 3 years postpartum in the Netherlands. Birth 2008; 35(2):107–116

20 van Stenus CM, Boere-Boonekamp MM, Kerkhof EF, Need A. Client satisfaction and transfers across care levels of women with uncomplicated pregnancies at the onset. Midwifery. 2017 May;48:11-17. doi: 10.1016/j.midw.2017.02.007. Epub 2017 Feb 28.

21 Green JM, Renfrew MJ, Curtis PA. Continuity of carer: what matters to women? A review of the evidence. Midwifery. 2000 Sep;16(3):186-96.

22 Perdok H, Verhoeven CJ, van Dillen J, Schuitmaker TJ, Hoogendoorn K, Colli J, Schellevis FG, de Jonge A. Continuity of care is an important and distinct aspect of childbirth experience: findings of a survey evaluating experienced continuity of care, experienced quality of care and women's perception of labor. BMC Pregnancy Childbirth. 2018 Jan 8;18(1):13. doi: 10.1186/s12884-017-1615-y.

23 Dahlberg U, Aune I. The woman's birth experience---the effect of interpersonal relationships and continuity of care. Midwifery. 2013 Apr;29(4):407-15.

24 de Jonge A, Stuijt R, Eijke I, Westerman MJ. Continuity of care: what matters to women when they are referred from primary to secondary care during labour? a qualitative interview study in the Netherlands. BMC Pregnancy Childbirth. 2014 Mar 17;14:103. doi: 10.1186/1471-2393-14-103.

25 Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. Cochrane Database Syst Rev. 2016 Apr 28;4:CD004667.

It is therefore likely that many traumatic experiences could be prevented if the community midwife could stay with her client after handover, and continue to deliver one-on-one continuity of care, as a team with hospital staff. This might change the way women feel about communication and support during labor. In the current system of Dutch maternity care, this continuity is difficult to achieve, since the case-load per community midwife per year is determined based on handing over a substantial percentage of clients, after which other activities can be employed. Even if community midwives were willing to stay and continue delivering care with extra monitoring and interventions provided by hospital staff, this would entail hospital staff allowing community midwives to deliver care in high risk births. This model of 'shared care' was the subject of the INCAS-2 study[26], which unfortunately was terminated prematurely due to an inability of different parties involved to reach an agreement on the definition of integrated maternity care. Rethinking the structure of Dutch maternity care, with its strict division between primary and secondary care, and decreasing the case-load per midwife substantially, might be a worthwhile investment in the prevention of traumatic birth experiences. In addition, if we aim to achieve continuity of care, more energy should be invested in training residents and student midwives together, so they become aware of each other's strengths and how these can be used to work together for the benefit of our clients.

Another possible cause for a traumatic experience is the birth not going according to expectations. Some women in Chapter 8 indicated they had no idea that their birth could still end in an instrumental vaginal birth or a cesarean section, never mind how large that chance was. In accordance with the 'Integral Birth Care Standard', we would therefore recommend a standard policy of counseling women with both the Dutch national statistics on different interventions during childbirth and the statistics of the local VSV, not in order to terrify them, but to create awareness that these outcomes are realistic possibilities for almost every first birth. It also seems wise to recommend all women write a birth plan, since discussing the birth plan may reveal certain unrealistic expectations women may have, and provide an opening for providers to give information about the likelihood and practicality of certain wishes or requests. In addition, shared decision making during birth should receive more attention. Use of the 'three questions intervention', in which women are presented with all options, the (absolute) risks and benefits of these options, and how likely they are to happen, has already been proven feasible in a clinical (birth) setting[27].

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26 http://www.incas2.nl/

27 Baijens SWE, Huppelschoten AG, Van Dillen J, Aarts JWM. Improving shared decision-making in a clinical obstetric ward by using the three questions intervention, a pilot study.BMC Pregnancy Childbirth. 2018 Jul 4;18(1):283.

Another item that requires consideration is 'Respectful Maternity Care (RMC)'. This is an important subject on the agenda of the WHO (World Health Organization), who recently released a statement recommending RMC for all women worldwide[28]. In November of 2016, an organization of women and providers known as 'the Birth Movement' (Geboortebeweging), organized a platform on facebook for women (and their partners) in analogy to the international #breakthesilence movement. This platform was called #genoeggezwegen,[29] and called on women to come forward with experiences of disrespect and abuse in Dutch maternity care. Many maternity care providers in the Netherlands felt that this was a 'third world issue', which does not feature in their country. However, the many women who participated in the #genoeggezwegen platform in 2016 disagreed. A PhD project, initiated by Amsterdam UMC, VU Midwifery Science, has started to investigate issues surrounding Respectful Maternity Care in the Netherlands. Finally, we would like to advocate for implementation of an antenatal screening tool for risk factors for a traumatic birth experience that we found in Chapter 9, such as 'Mind-2-Care'[30]. This would make it possible to identify women with low social support and lack of coping skills, and to offer them targeted supportive antenatal classes aimed at decreasing their vulnerability during birth, such as Centering Pregnancy[31], or an antenatal clinic ('POP-poli') designed for women with social, psychological or substance abuse problems.

Secondary prevention: preventing development of post partum PTSD

It is impossible to prevent all traumatic birth experiences. However, a traumatic experience does not necessarily have to become a post partum PTSD (Post Traumatic Stress Disorder). Currently, there is no strategy for screening for traumatic experiences during the standard post partum check six weeks after the birth. Although community midwives generally schedule follow up appointments with all their clients after six weeks, it is unknown how many women who give birth in secondary care are offered a follow up appointment, and if they are, it is not always with the person who was present during the birth. Since it is notoriously difficult to estimate who might have had a traumatic experience, we recommend that all women are offered an appointment with the

28 https://extranet.who.int/rhl/topics/preconception-pregnancy-childbirth-and-postpartum-care/care-during-childbirth/who-recommendation-respectful-maternity-care-during-labour-and-childbirth
29 http://geboortebeweging.nl/genoeggezwegen/
30 https://www.mind2care.nl/
31 https://www.centeringhealthcare.nl/zorgverleners/pregnancy/

care provider in charge of the birth. This recommendation will appear in the new NVOG guideline 'Birth related PTSD and PTSD-like complaints', which will become available in 2019. During this appointment, the woman's experience of the birth should always be discussed. If the provider feels the woman might have had a traumatic experience, we recommend asking her a few short screening questions, such as the TSQ[32]. If there is still a suspicion of trauma, with negative impact on the woman's emotional wellbeing, referral to the GP (general practitioner) for further diagnosis and referral is recommended.

Another suggestion for post partum checks would be to telephone all women three weeks after the birth, as is done in the Radboud University Hospital in Nijmegen. This way, almost all women will be reached, including those who did not plan on attending the six weeks check, or who were not offered an appointment. We also recommend offering all women, either by telephone or in person, the opportunity to come back any time to discuss the birth, even if the event was more than six weeks ago, since some women do not become aware that the experience was traumatic until (much) later[33].

Tertiary prevention: preventing negative choices for birth outside the system

Even without a traumatic childbirth experience, some women will always choose to give birth 'outside the system'. As explained in Chapters 3 and 7, they choose holistic care or a UC because this is in line with their way of life and how they feel about birth and a home environment. Since they do not require anything from regular maternity care providers, there will be no opportunity to discuss the risks and benefits of all possible options.

However, as Chapters 3, 4, 5 and 7 illustrate, most women who decline recommended care do so not because they are looking for something (positive choices), but because they are trying to avoid something (negative choices). They are trying to avoid a(-nother) traumatic experience, which they believe will happen if they agree to the management plan suggested by their maternity care providers. Negative choices are undesirable for both women and providers, and should be prevented as much as possible.

Maternity care providers faced with a birth plan which, in their opinion, requires them to deliver suboptimal care, are in a difficult position. On the one hand, everyone (including pregnant women) has easy access to the entirety of world literature on obstetrics, as well as to an abundance of grey literature, such as blogs and social media groups. Making a distinction between scientific

32 http://www.ggzveenendaal.nl/wp-content/uploads/2017/02/TSQ-screening-PTSS.pdf

33 de Visser SM et al. Major obstetric hemorrhage: Patients' perspective on the quality of care. Eur J Obstet Gynecol Reprod Biol. 2018 May;224:146-152.

evidence and lay opinion in this whirlpool of information is difficult, even for professionals, let alone those who are untrained. At the same time, women are told to take responsibility for their own health, manage their own personal health environment, and are encouraged to decide for themselves what care they want from professionals. On the other hand, providers are faced with an increasing multitude of protocols and guidelines, and can be held accountable for non-adherence during perinatal audits or discussions with their colleagues. In addition, even in the Netherlands, they feel threatened by the possibility of legal action being taken against them by either their clients or the health care inspection. Maternity care providers are therefore stuck between ever more well-informed and assertive clients, and ever narrowing margins in which they feel they can practice. And to make it even more difficult for both women and providers, due to several developments in the way we practice over the past few decades[34], there are more and more different providers involved in each and every pregnancy, making establishing a trusting relationship a challenge for all parties involved.

Therefore, if we, as professionals, want to avoid women making negative choices for a home birth in a high risk pregnancy, we will need a paradigm shift. The relationship between provider and client will truly have to be an equal partnership, in which we as professionals are not the ones who decide, but rather guide the client in reaching the decision that is most in line with her views and values. This means that the protocol or guideline is the starting point of the conversation, instead of the bottom line. We will have to practice actual shared decision making, since, as one reviewer for BMC Pregnancy and Childbirth put it, 'Shared decision making is an art often avowed but rarely practiced', and not, as so often is the case, 'I share my decision with you'. We will have to strive to involve the partner more (Chapter 5), to ensure that he or she is also aware of the risks and benefits of all possible options. We will have to learn how to recognize an imminent 'defining moment' (Chapter 7), so that we can attempt to turn the tide. We will have to document all conversations extensively and in detail, so it will be completely clear to anyone who looks that all relevant facts were discussed, and what choices the woman made based on all this information (Chapter 10). We will need to counsel with absolute risks, numbers needed to treat and needed to harm instead of odds ratios, and learn to communicate risk without appearing to be 'shroud waiving' (Chapter 3). When discussing birth plans, we will have to learn to start with the question: "What matters to you?" And if a woman has decided to have a home birth in a high risk

34 M.H. Hollander en J. van Dillen. Zorg op maat in de verloskunde, verklaard vanuit de geschiedenis. NTOG 2017;vol. 130

pregnancy with a holistic midwife, we will have to appreciate that that midwife is the only assistance this woman will except, and welcome both of them if they decide to ask for assistance during the birth (Chapter 4). Our professional organizations (and health care insurance companies) will have to work harder to achieve consensus on the importance and definition of continuity of care, in order to better establish a relationship of trust between ourselves and our clients, since that is an important contributing factor to our joint ability to reach a compromise with which both parties are comfortable (Chapter 10). Finally, we are going to have to try to teach all the above to our residents and midwifery students, who, in this era of 'putting the client first', are trained to follow protocol more than ever before. Indeed, if we are successful in teaching flexibility and the relative value of protocollized care, this may benefit not only women who decline recommended care, but all women in maternity care.

Limitations of this thesis

It is a hallmark of qualitative research that findings necessarily reflect the thoughts and opinions of only a small number of subjects. That is why it is always difficult to prove that the results of any qualitative study apply to an entire population. For this thesis, we interviewed, among others, 28 Dutch women who had given birth outside guidelines. There are of course many more women in the Netherlands who make this choice each year, whose opinions could in theory differ from these findings, not to mention elsewhere in the world. However, we reached saturation after 22 interviews, and our findings corresponded with those found in literature from other countries, confirming that women in the Netherlands have the same motivations as women in countries where home birth is not integrated in regular maternity care.

In order to elucidate why women experience childbirth as traumatic, we analyzed more than 2000 questionnaires. All these women had had a self reported traumatic birth experience. However, it is inherent to the design of this study, that there is as yet no information on whether or not their attributions are any different from women who did not have a traumatic experience, or from women who had a traumatic experience but decided not to respond on our questionnaire, either because their experience was too traumatic to want to relive, or because they had moved on and did not feel the need to revisit their birth.

This thesis currently offers the best available evidence why Dutch women might choose a home birth in a high risk pregnancy or a UC, why some midwives are willing to assist them, and what role their partners have in the decision making process, in addition to why Dutch women experience their birth as traumatic.

Recommendations for future research

In this thesis we describe why women want other or no delivery care, and why some women experience childbirth as traumatic. Although an association between the two is plausible, and indeed suggested in many interviews with both women, partners and maternity care providers, further quantitative studies are needed to investigate whether women with a traumatic birth experience more often choose care outside guidelines than women with a 'good' birth experience.

As reported above in our reply to question 3, the number of women declining recommended care is still unknown, despite our best efforts. To clarify this matter, we would have to start registering all home births in high risk pregnancies as a new category in the national perinatal registry. In addition, in order to register all UC's, we would have to make 'professional birth attendant' a mandatory question when registering a baby at town hall. Both of these new registrations will be a challenge, since some women who have had a UC or a home birth in a high risk pregnancy are afraid of being reported to child protective services, and may not want to disclose what they have done. Finally, there is no clear delineation between 'against medical advice' and 'against local custom' or 'outside my comfort zone'. Therefore, it will be difficult if not impossible to ask midwives and gynecologists to prospectively register all requests or refusals they encounter that were against their advice.

Another item that has not received enough attention thus far, is what emotional impact being confronted with a woman who refuses recommendations for interventions can have on maternity care providers. The 'CAPTURE' study group[35] has been investigating medical professionals' traumatic experiences, and we suggest incorporating this line of questioning in their next study among maternity care professionals.

At this junction, we want to stress the importance of qualitative research. It is often undervalued, since quantitative studies can demonstrate associations and information on the magnitude of certain problems, but only qualitative research can give insight in the reason(s) 'why'.

When it comes to traumatic experiences, there are two proven treatments for PTSD: Cognitive Behavioral Therapy and EMDR (Eye Movement Desensitization and Reprocessing). However, what is not currently known is whether or not these are also effective in cases of a trauma that does not meet all the criteria for PTSD, even though the burden of disease may be substantial. This also warrants more research.

35 http://capture-group.nl/

Finally, another subject that requires further study is how to (re-)shape Dutch maternity care, in order to provide more continuity of care and more one-on-one support during labor. Many issues, among others staffing shortages, finances and responsibilities play a part. Integral Birth Care may be the title of the new Standard, but in most areas of the country, the items listed here are still far from a reality.

Conclusions

From the articles included in this thesis, the following conclusions can be drawn:

- When women refuse certain items of recommended care, this is not a conflict of interest between mother and child, but a doctor-patient conflict.
- The main goal of working with women whose birth choices do not align with medical advice should be to prevent negative choices.
- 'Holistic' midwives deliver an important service because for some women they are the last resort before those women choose to give birth unassisted.
- Partners of women who go against medical advice in their birth choices receive most information on risks and benefits of different management strategies from their wives/girlfriends, and should be more involved by professionals during consultations in order to be able to make an informed choice.
- Requests for more and less birth care than recommended are equally prevalent in the Netherlands, however, a request for less care is more likely to be declined.
- A trusting relationship based on continuity of care, actual shared decision making and awareness by caregivers of their own concepts of risk perception may help to make more women perceive the hospital as safe again.
- Women attribute their traumatic childbirth experiences primarily to lack and/or loss of control, failing communication and lack of practical/emotional support from their caregivers.
- Low social support, poor coping, experiencing 'threatened death' and experiencing 'actual or threatened injury to the baby' are significant factors in a predictive model for women with a traumatic childbirth experience to be at risk of developing post partum PTSD.
- Following a systematic multidisciplinary approach in the outpatient clinic may help maternity care providers to reach a consensus with women who decline recommended care, which will prevent worse choices and possible bad outcomes.

12

Developments since the start of this project

In November of 2015, the Royal Dutch Organization of Midwives (KNOV) and the Dutch Organization of Obstetrics and Gynecology (NVOG) released a new multidisciplinary guideline "Maternity Care outside Guidelines", detailing how maternity care providers should act when their clients intend to decline items of recommended care. This was necessary, as the subject had by then become a hot topic in the Netherlands, with much debate and many differing opinions discussed at conferences and symposia, both nationally and internationally. Both professional organizations believed that the field needed help implementing this guideline. Therefore, the two midwives and the obstetrician who were the main authors, in addition to the author of this thesis were asked to organize training sessions for representatives of all Maternity Care Networks of midwives and gynecologists (Dutch: VSV/Verloskundig Samenwerkings Verband). Over the next year and a half, more than two thirds of networks in the Netherlands were trained. We encountered many different viewpoints, from open and curious, to outright hostile. Our experiences with teaching the guideline were reported in the Dutch Midwifery Journal (TVV)[36].

In 2016, the Dutch National Health Care Institute introduced the 'Integral Birth Care Standard' (Zorgstandaard). This document outlined the direction maternity care in the Netherlands should take in the coming years, with an emphasis on new levels of cooperation between primary and secondary care providers. It emphasizes putting the client first through shared decision making, and stresses the importance of adherence to the guideline mentioned above, as well as encourages hospitals to introduce water births and single room maternity concepts[37].

New developments in patient empowerment include nationwide (and international) efforts to involve patients in evaluating the care they received, including women who have given birth. One of the organizations working on this is ICHOM (International Consortium for Health Outcome Measures), which bases itself on the principle of value-based health care, and not only evaluates patient reported outcome measures (PROM's), such as survival and morbidity, but also patient reported experience measures (PREM's), such as patient-reported health and well-being and patient satisfaction with care. ICHOM therefore puts an emphasis on information that matters to women, up to six months after the birth, such as bonding with the child, and confidence in her role as a mother. Data gathered through the recommended ICHOM standard set for pregnancy and childbirth can help both maternity care providers and women with deci-

36 M.H. Hollander, R. Visser, M. Boddé en G. Kleiverda. Verloskundige zorg buiten richtlijnen; enthousiast aan de slag. TVV 2018;03

37 https://www.knov.nl/serve/file/knov.nl/knov_downloads/2564/file/Zorgstandaard_Integrale_Geboortezorg_1._28_juni_20161.pdf

sion-making during consultations. This development is consistent with the trend to evaluate care not only based on 'hard' outcome measures, but also on what patients report that matters to them. Another example of involving patients in the evaluation of care in the Netherlands is the nationwide introduction of the Net Promotor Score (NPS), which became mandatory in 2018. The NPS consists of one question: "How likely is it that, based on your experiences with care surrounding pregnancy/birth, you would recommend (this VSV) to a friend? Finally, NIVEL (Netherlands Institute for Health Services Research) has introduced the CQ Index (Consumer Quality Index)[38], which measures quality of care from the patient perspective and is used by care providers to compare their experienced care with that of similar providers.

All these developments are very promising, but there is a pitfall: it could be tempting to believe that asking your clients for their evaluations is enough to demonstrate that you are involving your client in the care you provide. However, just listing numbers and percentages is not enough. The challenge is not only to gather the information, but to actually use it for quality improvements. Really putting the client in the central position needs a paradigm change from care centered around what the professional has to offer, to care centered around what the client wants. The data gathered through ICHOM should be used to effect actual change during consultations.

In recent years, there have been a few other new developments in the field of maternity care relating to problems discussed in this thesis. In the summer of 2016, the first Dutch breech conference took place in Amsterdam, introducing the concept of upright breech birth to an enthusiastic audience of midwives and gynecologists[39]. This was an imported event, since several cases of home breech births investigated in this thesis started out with a wish for upright breech birth, and a provider's refusal to facilitate this.

This past year, another legal case made the news in the Netherlands. This time it was a civil suit, where a pregnant woman with a previous cesarean section sued a hospital for not allowing her to give birth with her own holistic midwife. She wanted a home-like birth, but still within the relative safety of the hospital. This was denied by her local court[40], stating that she was of course free to refuse any interventions she chose, but could not demand alternative care. This is opposite to the strict recommendations in the professional guideline of NVOG and KNOV mentioned above, regarding 'Maternity Care outside Guidelines', which state that 'second best care' is preferable to no care. Due to this ruling, more women could potentially be faced with a hospital's denial of 'second best

38 https://www.nivel.nl/nl/cq-index
39 https://www.talmor.nl/impressie/first-amsterdam-breech-conference-teach-the-breech/
40 https://uitspraken.rechtspraak.nl/inziendocument?id=ECLI:NL:RBZWB:2018:1745

care', and feel themselves left with no other choice than to have a home birth in a high risk pregnancy or a UC, as several similar cases in Chapter 3 have demonstrated. The appeal of this case is still pending.

Several developments are currently ongoing: the NVOG committee 'gynecologist and society' (Gynaecoloog en Maatschappij), responsible for commissioning the new guideline "Maternity Care outside Guidelines", is planning on investigating how implementation is progressing in each region of the country, and what barriers colleagues are experiencing in adhering to this guideline and negotiating with women who decline their advice. In addition, a national symposium for midwives and gynecologists is being organized, which will cover virtually all results that can be found in this thesis. Finally, training sessions for networks (VSV's) concerning implementation of this new guideline are now being organized locally, for all members of the network in question, and will provide training tailored to local needs and dilemma's.

In summary, in the Netherlands, the last few years have seen a trend towards putting pregnant women's needs and wishes first, and using protocols and guidelines only as a starting point for negotiations about a birth plan. If the recommendations for prevention in this thesis are widely implemented, we will hopefully find this will result in even more positive birth experiences.

13

Summary/Samenvatting

Summary

This summary will list the different chapters of this thesis, and explain the main findings of each study.

In this thesis, we examine the phenomenon of women choosing to go against medical advice in their choices for giving birth, a topic which is cause for much debate among professionals and women alike. There are many "stakeholders" involved: first and foremost of course, the women themselves. But also: their partners, their obstetricians, their community midwives and the holistic midwives who attend the home births in high risk pregnancies that take place among this group. Last, but not least, of course, there are the children these women are carrying.

Most women who choose to 'birth outside the system' do not make this choice early on during their first pregnancy. In many cases, traumatic experiences during the previous birth, or the current pregnancy, play a large part in their decision. Therefore, it appears that insight into the root causes of these traumas is vital to gaining a full understanding of the decision-making process which precedes these choices.

Chapter 1 is the introduction of this thesis, and describes the events leading up to the inception of this project. In addition, we describe the two studies that were conceived: the 'Wonderstudy' (Why women want Other or No DElivery caRe), which studied the phenomenon of birthing outside the system, and comprises chapters 3-7, and the TEACH study (Traumatic Experiences Associated with CHildbirth), which investigated why women experienced childbirth as traumatic, and comprises chapters 8 en 9.

Chapter 2 outlines the legal and ethical intricacies of situations where pregnant women and their maternity care providers disagree on a birth plan. Women may opt for a birth in a setting that is against recommendations, for instance a home birth in a high risk pregnancy. Alternatively, they may request to have a hospital birth with a community midwife, in a situation in which this is against medical advice, for instance a breech or twin birth, or they may refuse certain items of recommended care, such as continuous fetal monitoring during a trial of labor after a previous cesarean section. In these situations, medical professionals may feel as if there is a conflict between the wishes of the woman and the best interests of the baby she carries. This may lead providers to resort to measures such as coercion, or actual force, such as a court-ordered cesarean section. In this chapter, we outline the positions of various professional organizations pertaining to coercion and force, and illustrate that it is actually the professional the woman is in conflict with, and not the baby she is carrying. We conclude by stating that, in the great majority of cases, actual shared decision

making will resolve the issue, and if not, the autonomy of the woman should always prevail.

In **Chapter 3**, we report the results of interviews with 28 women who chose a home birth in a high risk pregnancy, or an unassisted childbirth (UC). Four major themes were found: discrepancy in the definition of superior knowledge, need for autonomy and trust in the birth process, conflict during negotiation of the birth plan, and search for different care. One overarching theme emerged, which was 'Fear'. Women feared not only unnecessary interventions which might lead to a traumatic experience, they also feared the providers' fear of a bad outcome and legal ramifications, which in itself could lead to defensive medicine. The main finding of this study was that, for the majority of women, the choice to have a home birth in a high risk pregnancy or a UC was a negative one. This means that they did not make this choice because they believed that home, or unassisted, was the best way for them to give birth, rather, they had a negative experience in maternity care, or a conflict surrounding their wishes for the birth plan. This made them decide that this was the only way they could give birth the way they wanted to, and believed was best for themselves and their child(-ren). This insight has led to recommendations for caregivers that include ways to discuss risk that are non-coercive, neutral and without instilling fear. This makes it possible to practice actual shared decision making, and demonstrates willingness to discuss second best options by being flexible about birth plans.

Chapter 4 describes the findings of interviews with 24 midwives, who are willing to assist women with a high risk pregnancy during a home birth. Internationally, they are referred to as 'holistic', which we have done as well. Holistic midwives are community midwives, who have decided to not let guidelines and protocols prevail in deciding what care they deliver to their clients. Instead, they let themselves be guided by the needs of their clients, with whom they establish a close relationship built on mutual trust. This study showed that the majority of holistic midwives work in case-load practices, often alone, sometimes with a partner. The overarching theme in all these interviews was 'Addressing a need'. Holistic midwives felt that the regular system was not meeting women's needs, and that they were the last safety net between women who have opted for a home birth in a high risk pregnancy and a UC, since the regular system lacked flexibility. This chapter concludes with the assertion that holistic midwives, though not always providing care according to guidelines and protocols, deliver an important service, without which more women might deliver unassisted. In addition, if regular maternity care professionals would be more flexible during negotiations of certain birth plans, many women who now turn to holistic midwives might be willing to stay in regular care.

In **Chapter 5,** we discuss the involvement of partners in the decision to give birth at home in a high risk pregnancy, or opt for a UC. Twenty-one partners were interviewed about the process that led up to the decision to birth outside the system. The main theme that was found, was 'She convinced me'. This study shows, that the idea to go against medical advice in birth choices almost invariably originates with the woman. She does the research herself, mostly online, filters the information, and convinces the partner of the merit of her plans. Once convinced, the partners take on the task of defending the plan to their own social circle and actively participate in planning and preparing for the birth. This article concludes with the recommendation to involve partners pro-actively in antenatal visits to ensure that they too receive information on all options, risks and benefits of possible birth choices.

For **Chapter 6**, we explored the experiences of Dutch midwives and gynecologists with pregnant women who request either more or less care during pregnancy and/or childbirth. This chapter describes the results of a questionnaire distributed among all registered maternity care professionals in the Netherlands (N=4141). 900 Questionnaires were returned, for a response of 21.7%. Most professionals encountered at least one request for less care than indicated per year. Women who desired less care included women declining hospital birth in a high risk pregnancy, testing for diabetes, fetal monitoring, and desiring a UC. Most requests per person were received by holistic midwives. An approximately equal percentage of professionals received at least one request per year for more care than indicated. The majority of these requests consisted of elective inductions and non-medically indicated cesarean sections. The main finding of this study was that a request for more care was less likely to be declined than a request for less care.

In **Chapter 7** we performed an in-depth analysis of some of the cases described in chapters 3, 4 and 5. For 10 cases, the interviews with the woman, her partner and her professionals (both regular and holistic) were combined, to determine if there was a pattern, through which the decision to go against medical advice was reached. In all but one of the 10 cases, it was possible to identify a trajectory of trauma, self-education and conflict over the birth plan, leading to a negative choice for holistic care, where the hospital was no longer seen as an option. In the 10th case, the path followed was one of trust in nature, and a positive choice for holistic care. Recommendations from this study consist of suggestions for ways of making the hospital feel safe again through continuity of care, flexibility in dealing with requests outside guidelines and shared decision making, and by doing so, preventing the original trauma.

The previous chapters has shown that trauma plays a large part in women's choices for a birth against medical advice. **Chapter 8** contains the results of a

study investigating what women themselves believe caused them to have a traumatic childbirth experience. As opposed to previous studies, which only demonstrated associations between certain birth complications and traumatic experiences, we disseminated a questionnaire through social media such as facebook and twitter to ask women themselves what they believed made their birth experience a traumatic one, and how it could have been prevented. During the first 48 hours we received 1500 responses, and overall more than 2000 women filled out the questionnaire. The results of this survey demonstrate that women attribute their traumatic childbirth experience primarily to lack and/or loss of control, issues of communication, and practical and/or emotional support. This study shows that, although a traumatic childbirth experience is often associated with certain birth complications, it is not the occurrence of the complication in itself that causes the experience to be a traumatic one, rather, a lack of communication and support from the provider.

In **Chapter 9**, we take a closer look at women who experienced childbirth as traumatic. We aimed to investigate a model which could predict which women with a traumatic experience would develop post partum PTSD (post traumatic stress disorder). This study found that women with low social support, poor coping skills and those who had experienced threatened or actual death or injury to the baby were most at risk of developing post partum PTSD. We concluded by stating that this study supports efforts to identify women vulnerable to a traumatic childbirth experience due to low social support, poor coping skills and increased risk of unfavorable obstetrical outcomes, and to develop a strategy for interventions aimed at prevention.

In **Chapter 10** we report on the structure and results of a dedicated outpatient clinic for women who decline certain items of care in their birth plans. Women are referred to this clinic by midwives from the catchment area of the hospital, by other hospitals in the region or by colleagues in-house, when they submit a birth plan that goes against the recommendations of their provider. Through a systematic, multidisciplinary approach, women are given ample time to explain their wishes and reasoning, are counseled with absolute risks, numbers needed to treat and –harm, and shared decision making is practiced. In addition, maternity care providers at this clinic are open to requests against medical advice, explore these requests in a structured manner, and attempt to reach a compromise. If necessary, a 'moral case deliberation' is organized. Through this way, more than a third of birth plans ended up inside protocol, and another third consisted of a compromise acceptable to all parties. After the final consultation, 1 in 4 women found themselves unable to agree to a compromise and gave birth elsewhere. This study shows that, through a structured approach with actual shared decision making, the majority of women is willing to adjust

their birth plan and a compromise can be reached. Providers are open to requests outside guidelines, ask questions and are willing to make compromises because the woman and her choice come first, even if that choice deviates from protocol, and protocol does not determine policy. We suggest the possibility that this would have caused most of the women reported on in chapter 7 to agree to give birth in the hospital instead of proceeding with their plans for a home birth in a high risk pregnancy.

Chapter 11 comprises the general discussion of this thesis. In this thesis, we have shown that some women decide to go against medical advice in opting for a high risk home birth or a UC. In the cases of the women in our study, this decision was almost invariably preceded by a traumatic experience during a previous birth, or in the current pregnancy, which led women to devise a birth plan aimed at preventing a repetition of the trauma. These birth plans then caused conflicts, during which women perceived professionals as lacking in flexibility, respect and shared decision making, all of which they found in their holistic midwives. Women who are planning a birth outside the guidelines are generally highly educated and very well informed, by doing their own research on the internet and through social media. In our study, partners reported being convinced by their wives/girlfriends' research, and supporting the final birth plan.

In the discussion, we elaborate on the reasons why there appears to be a growing discrepancy between what women want from care providers, and what the latter are comfortable delivering. We discuss recommendations for professionals, pertaining to prevention of the original trauma, practicing actual shared decision making and passing on this knowledge to the next generation.

Finally, we discuss directions for future research, including the quantitative link between traumatic birth experiences and birth choices against medical advice.

Samenvatting

In deze samenvatting worden de verschillende hoofdstukken van dit proefschrift op een rij gezet en de belangrijkste bevindingen van elk onderzoek benoemd.

In het onderzoeksproject dat ten grondslag ligt aan dit proefschrift onderzoeken we het fenomeen dat sommige vrouwen ingaan tegen medisch advies bij hun keuzes rondom de bevalling. Een onderwerp dat veel stof doet opwaaien, zowel onder beroepsbeoefenaars als onder vrouwen zelf. Er zijn veel 'belanghebbenden': om te beginnen natuurlijk de vrouwen zelf, maar ook hun partners, gynaecologen, eerstelijns verloskundigen en de holistische vroedvrouwen die de thuisbevallingen met medische indicatie bij deze groep begeleiden. Tenslotte, en zeker niet onbelangrijk, zijn er de kinderen die deze vrouwen dragen.

De meeste vrouwen die ervoor kiezen om te bevallen 'buiten de richtlijnen' nemen dit besluit niet aan het begin van hun eerste zwangerschap. In veel gevallen spelen traumatische ervaringen rondom de vorige bevalling of tijdens de huidige zwangerschap een grote rol bij hun beslissing. Het lijkt derhalve van vitaal belang om inzicht te verwerven in de onderliggende oorzaak van deze trauma's, teneinde volledig inzicht te krijgen in het besluitvormingsproces dat vooraf gaat aan deze beslissingen.

Hoofdstuk 1 is de inleiding van dit proefschrift en beschrijft de gebeurtenissen die aanleiding waren voor het ontstaan van dit project. Vervolgens beschrijven we de twee studies die zijn ontworpen: de WONDER studie (Why women want Other or No DElivery care), die het fenomeen van bevallen buiten de richtlijnen onderzocht en hoofdstukken 3-7 omvat, en de TEACH studie (Traumatic Experiences Associated with Childbirth), die onderzocht waarom vrouwen hun bevalling traumatisch vonden, en hoofdstukken 8 en 9 betreft.

Hoofdstuk 2 beschrijft de juridische en ethische knelpunten van situaties waarin zwangere vrouwen en hun zorgverleners het oneens zijn over een bevalplan. Vrouwen kunnen kiezen voor een plaats van de bevalling die tegen medisch advies is, bijvoorbeeld een thuisbevalling bij een hoog risico zwangerschap. In plaats daarvan kunnen ze ook vragen om een ziekenhuisbevalling met hun eigen eerstelijns verloskundige in een situatie waarin dat tegen medisch advies is, bijvoorbeeld bij een stuitbevalling of een tweeling, of ze kunnen bepaalde onderdelen van geadviseerde zorg weigeren, bijvoorbeeld continue foetale bewaking tijdens een bevalling na een eerdere sectio cesarea. In deze situaties kunnen medisch professionals een conflict ervaren tussen de wensen van de vrouw en de belangen van het kind dat zij draagt. Dit kan zorgverleners ertoe brengen hun toevlucht te nemen tot drang of zelfs dwang, zoals bij een gedwongen keizersnede. In dit hoofdstuk geven we een overzicht van de standpunten van verschillende beroepsorganisaties met betrekking tot

drang en dwang, en illustreren we dat het in feite een conflict betreft tussen de vrouw en de zorgverlener, en niet tussen de belangen van de vrouw en die van de baby die ze draagt. We eindigen ons betoog met de stelling dat het overgrote deel van de gevallen opgelost kan worden door daadwerkelijke 'shared decision making'. Indien dit niet mogelijk blijkt dan zou de autonomie van de vrouw altijd moeten prevaleren.

In **Hoofdstuk 3** rapporteren we de resultaten van interviews met 28 vrouwen die kozen voor een thuisbevalling bij een medische indicatie, of een unassisted childbirth (UC). Vier hoofdthema's kwamen naar voren: discrepantie in de definitie van superieure kennis, behoefte aan autonomie en vertrouwen in het geboorteproces, conflict tijdens de onderhandeling over het bevalplan en zoektocht naar andere zorg. Er was één overkoepelend thema, namelijk 'Angst'. Vrouwen waren niet alleen bang voor onnodige interventies die een traumatische ervaring tot gevolg zouden kunnen hebben, ze waren ook bang voor de angst van zorgverleners, die op haar beurt dan weer zou kunnen leiden tot defensieve geneeskunde. De belangrijkste bevinding van dit onderzoek was dat, voor de meerderheid van de vrouwen, de keuze voor een thuisbevalling bij een medische indicatie (of voor UC) een negatieve keuze was. Dit betekent dat ze deze keuzes niet maakten omdat ze ervan overtuigd waren dat thuis, of unassisted, de beste manier was om te bevallen, maar dat ze een negatieve ervaring hadden met de verloskundige zorg, of een conflict rondom het bevalplan. Dit leidde tot de overtuiging dat dit de enige manier was waarop ze konden bevallen zoals zij dat wilden en waarvan ze geloofden dat die het beste was voor hen en hun kinderen. Dit inzicht heeft geleid tot aanbevelingen voor zorgverleners die onder andere betrekking hebben op manieren om risico's te bespreken die geen angst aanjagen, neutraal en zonder drang zijn. Hierdoor is het mogelijk om daadwerkelijk 'shared decision making' toe te passen, om bereid te zijn om second best oplossingen te overwegen en om flexibel te zijn bij de bespreking van het bevalplan.

Hoofdstuk 4 beschrijft de uitkomsten van interviews met 24 vroedvrouwen, die bereid zijn om vrouwen met een medische indicatie bij te staan bij een thuisbevalling. In internationale literatuur worden zij 'holistisch' genoemd, hetgeen wij hebben overgenomen. Tot de holistische vroedvrouwen behoren de eerstelijns verloskundigen die besloten hebben om richtlijnen en protocollen niet de doorslag te laten geven bij welke zorg zij bereid zijn te leveren aan hun cliënten. In plaats daarvan laten zij zich leiden door de behoeften van hun cliënten, met wie ze een nauwe band opbouwen gebaseerd op wederzijds vertrouwen. Dit onderzoek toont aan dat het merendeel van de holistische vroedvrouwen in case-load praktijken werkt, vaak alleen, soms met een partner. Het overkoepelende thema in al deze interviews was 'Voorzien in een behoefte'. Holistische vroedvrouwen vonden dat het reguliere systeem onvoldoende

tegemoet kwam aan de behoeften van vrouwen. Zij zijn het laatste vangnet tussen vrouwen die kozen voor een thuisbevalling bij een medische indicatie en een UC omdat het reguliere systeem onvoldoende flexibel was. Dit hoofdstuk besluit met de vaststelling dat holistische vroedvrouwen, hoewel ze niet altijd werken volgens richtlijnen en protocollen, een belangrijke dienst verlenen zonder welke er wellicht nog meer vrouwen unassisted zouden bevallen. Als reguliere verloskundige zorgverleners meer open zouden staan voor de wensen van de zwangere bij gesprekken over sommige bevalplannen, zouden vrouwen die nu een beroep doen op holistische verloskundigen wellicht bereid zijn om binnen de reguliere zorg te blijven.

In **Hoofdstuk 5** bespreken we de betrokkenheid van partners bij de beslissing om thuis te bevallen bij een medische indicatie of om voor UC te kiezen. Eenentwintig partners werden geïnterviewd over het proces dat uiteindelijk leidde tot de beslissing om buiten de richtlijnen te bevallen. Het overkoepelende thema was 'Zij heeft me overtuigd'. Dit onderzoek toont aan dat het idee om buiten de richtlijnen te gaan bevallen in vrijwel alle gevallen van de vrouw komt. Zij doet zelf onderzoek, veelal online, filtert de informatie en overtuigt de partner van haar plannen. Eenmaal overtuigd nemen de partners de taak op zich om hun gezamenlijke plan te verdedigen tegen hun vrienden en familie, en doen ze actief mee in het plannen en voorbereiden van de bevalling. Dit artikel eindigt met de aanbeveling om partners meer te betrekken bij zwangerschapscontroles, zodat ook zij beschikken over informatie over alle opties, risico's en voordelen van alle mogelijke keuzes rondom de bevalling.

Voor **Hoofdstuk 6** inventariseerden we de ervaringen van Nederlandse verloskundigen en gynaecologen met zwangere vrouwen die ofwel meer, ofwel minder zorg wensen tijdens zwangerschap en/of de bevalling dan aanbevolen. Dit hoofdstuk beschrijft de resultaten van een enquête die verspreid werd onder alle verloskundige zorgverleners in Nederland (N=4141). We ontvingen 900 enquêtes retour, hetgeen een respons betekent van 21.7%. De meeste zorgverleners kregen tenminste één verzoek voor minder zorg dan aanbevolen per jaar. Dit betrof onder andere vrouwen met een medische indicatie die niet in het ziekenhuis wilden bevallen, het weigeren van screening op diabetes gravidarum of foetale bewaking, en de wens tot UC. Holistische vroedvrouwen kregen de meeste verzoeken per persoon. Een vergelijkbaar percentage zorgverleners kreeg minstens één verzoek per jaar voor méér zorg dan geadviseerd. De meerderheid van deze verzoeken bestond uit verzoeken om inleidingen zonder medische reden of om electieve keizersneden. De belangrijkste bevinding van dit onderzoek was dat een verzoek om méér zorg minder vaak werd afgewezen dan een verzoek om minder zorg.

In **Hoofdstuk 7** voerden we een diepgaande analyse uit van sommige van de casussen die beschreven zijn in hoofdstukken 3, 4 en 5. Van 10 casussen werden de interviews met de vrouw, haar partner, en haar zorgverleners (zowel regulier als holistisch) gecombineerd om te bepalen of er een patroon te herkennen was in hoe het besluit om in te gaan tegen medisch advies tot stand gekomen was. In op één na alle gevallen bleek het mogelijk om een patroon te identificeren van trauma, zelf op zoek gaan naar medische informatie, en conflict rondom het bevalplan leidend tot een negatieve keuze voor holistische zorg, waarbij het ziekenhuis niet langer als een mogelijkheid werd beschouwd. In de 10e casus was het gevolgde pad er één van vertrouwen in de natuur, en een positieve keuze voor holistische zorg. Aanbevelingen uit dit onderzoek bevatten onder andere suggesties hoe het ziekenhuis weer veilig te laten voelen door continuïteit van zorg, flexibeler omgaan met zorgvragen buiten de richtlijnen, en shared decision making, waardoor in veel gevallen ook het oorspronkelijke trauma voorkómen kan worden.

De voorgaande hoofdstukken hebben aangetoond dat trauma een grote rol speelt in de keuze van vrouwen om tegen medisch advies in te gaan rondom de bevalling. **Hoofdstuk 8** bevat de resultaten van onderzoek naar wat vrouwen zelf benoemen als oorzaken van een als traumatisch ervaren bevalling. In tegenstelling tot eerder onderzoek, dat slechts associaties aantoonde tussen bepaalde verloskundige complicaties en traumatische ervaringen, besloten wij om, middels een enquête via social media zoals facebook en twitter, vrouwen zélf te vragen wat zij dachten dat de oorzaak was van hun traumatische ervaring, en hoe die voorkómen had kunnen worden. Tijdens de eerste 48 uur ontvingen we al 1500 reacties, en in totaal vulden meer dan 2000 vrouwen de vragenlijst in. De resultaten van deze enquête laten zien dat vrouwen hun traumatische bevallingservaring met name wijten aan gebrek aan/verlies van controle, problemen rondom communicatie, en gebrek aan praktische/emotionele ondersteuning. Dit onderzoek toont aan dat, hoewel een traumatische bevallingservaring vaak geassocieerd is met bepaalde verloskundige complicaties, het niet het optreden van de complicatie zelf is die het trauma veroorzaakt, maar een gebrek aan communicatie en ondersteuning van de zorgverlener.

In **Hoofdstuk 9** kijken we naar de achtergronden van de vrouwen die hun bevalling als traumatisch hadden ervaren. Het doel van dit onderzoek was om een model te ontwikkelen dat kan voorspellen welke vrouwen met een traumatische bevallingservaring een post partum PTSS (post traumatische stress stoornis) zullen gaan ontwikkelen. Dit onderzoek toonde aan, dat vrouwen met een klein sociaal netwerk, slechte coping vaardigheden en zij die daadwerkelijke of dreigende dood of schade van de baby hadden ervaren het grootste risico hadden om post partum PTSS te ontwikkelen. We concludeerden

dat dit onderzoek het idee ondersteunt om vrouwen die door een klein sociaal netwerk, weinig coping vaardigheden en een hoog risico op obstetrische complicaties at risk zijn voor een traumatische bevallingservaring, van tevoren te identificeren, en om een strategie voor interventies te ontwikkelen gericht op preventie.

In **Hoofdstuk 10** beschrijven we de aanpak en resultaten van een speciale poli voor vrouwen die in hun bevalplan bepaalde onderdelen van aanbevolen zorg weigeren. Vrouwen worden naar deze poli verwezen door verloskundigen uit het verzorgingsgebied van het ziekenhuis, door andere ziekenhuizen in de regio en door eigen collega's van de afdeling, als ze een bevalplan hebben opgesteld dat ingaat tegen het advies van de eigen zorgverlener. Door een systematische multidisciplinaire aanpak krijgen vrouwen ruimschoots de tijd om hun wensen en de achterliggende gedachten uit te leggen, worden ze gecounseld met behulp van absolute risico's, numbers needed to treat en –harm, en wordt 'shared decision making' toegepast. Bovendien staan zorgverleners van deze poli open voor vragen buiten advies, diepen ze die vragen gestructureerd uit en zoeken naar een compromis. Indien nodig wordt er een 'moreel beraad' georganiseerd. Op deze manier eindigde meer dan een derde van de bevalplannen binnen protocol, en bestond nog eens een derde uit een compromis dat voor alle betrokkenen acceptabel was. Na het laatste gesprek bleek dat 1 op de 4 vrouwen zich nog altijd niet kon vinden in een compromis. Zij zijn uiteindelijk elders bevallen. Dit onderzoek toont aan dat door een gestructureerde aanpak met daadwerkelijke shared decision making de meerderheid van de vrouwen alsnog bereid is haar bevalplan aan te passen, zodat een compromis kan worden bereikt. Hierbij wordt opengestaan voor verzoeken buiten de richtlijnen, wordt doorgevraagd en is bereidheid om compromissen te sluiten, omdat daadwerkelijk de vrouw en haar keuze centraal worden gesteld, ook als die afwijkt van het protocol, en het protocol niet als leidend wordt gezien. We suggereren de mogelijkheid dat dit bij de meeste van de vrouwen uit hoofdstuk 7 geleid zou hebben tot de bereidheid om toch in het ziekenhuis te bevallen, in plaats van door te zetten met hun plannen voor een thuisbevalling bij een medische indicatie.

Hoofdstuk 11 bevat de algemene discussie van dit proefschrift. In dit proefschrift hebben we aangetoond dat sommige vrouwen ervoor kiezen om tegen medisch advies in thuis te bevallen bij een medische indicatie, of te kiezen voor een UC. In de gevallen van de vrouwen in ons onderzoek werd deze keuze vrijwel steeds voorafgegaan door een traumatische ervaring tijdens een eerdere bevalling of in de huidige zwangerschap, die aanleiding was voor de vrouwen om een bevalplan op te stellen gericht op preventie van herhaling van het trauma. Deze bevalplannen veroorzaakten vervolgens conflicten waarbij de

vrouwen een gebrek aan flexibiliteit, respect en 'shared decision making' ervoeren bij hun zorgverleners. Dit vonden ze vervolgens wel bij hun holistische verloskundigen. Vrouwen die een bevalling buiten de richtlijnen plannen zijn doorgaans hoog opgeleid en zeer goed geïnformeerd, doordat ze hun eigen literatuuronderzoek doen op het internet en via social media. In ons onderzoek vertellen partners dat ze overtuigd zijn door het onderzoek van hun vrouwen/vriendinnen, en volledig achter het bevalplan staan.

In de discussie wordt dieper ingegaan op de redenen dat er een toename lijkt te zijn van de discrepantie tussen wat vrouwen vragen van hun zorgverleners, en wat die laatsten bereid zijn te leveren. Er worden aanbevelingen besproken voor zorgverleners die betrekking hebben op preventie van het oorspronkelijke trauma, daadwerkelijk shared decision making toepassen, en deze kennis overdragen op de volgende generatie zorgverleners.

Tenslotte worden onderwerpen voor toekomstig onderzoek besproken, inclusief de kwantitatieve link tussen traumatische bevallingservaringen en de keuze om te bevallen buiten de richtlijnen.

14

List of abbreviations and terminology
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List of abbreviations and terminology

Actio Caesarea	Suggested change in law to make court ordered cesareans possible in the Netherlands
'Birth Movement'	A foundation advocating for the rights of women in Dutch maternity care (http://geboortebeweging.nl/)
BMI	Body Mass Index
Case-load midwife	Midwife who accepts a small number of clients per month, is the main care provider both during pregnancy and birth, and spends more time per consultation than midwives in group practices
CBS	Central Bureau of Statistics
CDMR	Cesarean Delivery at Maternal Request
C-section	Cesarean section
CTG	CardioTocoGraphy
CQ Index	Consumer Quality Index
EBM	Evidence Based Medicine
EMDR	Eye Movement Desensitization and Reprocessing
GP	General Practitioner (family doctor)
Holistic Midwife	Holistic midwives frequently work as case-load midwives. Their view on maternity care centers around their client's wishes, rather than what protocols and guidelines recommend. They are often willing to honor requests for care that do not align with protocols or guidelines.
ICHOM	International Consortium for Health Outcome Measures
INCAS-2	INtegrated CAre System-2 (http://www.incas2.nl/)
KNOV	Koninklijke Nederlandse Organisatie van Verloskundigen (Royal Dutch Organization of Midwives)
LMWH	Low Molecular Weight Heparin
Mind-2-Care	Screening programme for social and psychological vulnerabilities (https://www.mind2care.nl/)
MPV	History of Manual Placental Removal
NICU	Neonatal Intensive Care Unit
NIVEL	Nederlands Instituut voor Onderzoek van de Gezondheidszorg (Netherlands Institute for Health Services Research) (www.nivel.nl)
NPS	Net Promotor Score
NVOG	Nederlandse Vereniging voor Obstetrie en Gynaecologie (Dutch Organization of Obstetrics and Gynecology)
OB/GYN	Obstetrics and Gynecology
PERINED	Perinatal Registry Netherlands
PERISTAT	Perinatal Statistics (www.peristat.com)
POP-poli	Outpatient clinic for Psychiatry, Obstetrics and Pediatrics
PPH	Post Partum Hemorrhage > 1000 ml in previous delivery

PREM's	Patient Reported Experience measures
PROM's	Patient Reported Outcome Measures
PROM	Prelabor Rupture of Membranes
PTSD	Post traumatic Stress Disorder
RMC	Respectful Maternity Care
TEACH-study	Traumatic Experiences Associated with Childbirth (http://capture-group.nl/teach-studie/)
TVV	Tijdschrift Voor Verloskundigen (Dutch Midwifery Journal)
UC	Unassisted Childbirth
UK	United Kingdom
USA	United States of America
VBAC	Vaginal Birth After Cesarean
VSV	Verloskundig Samenwerkings Verband (Maternity Care Networks of midwives and gynecologists)
WHO	World Health Organization
WONDER-study	Why women want Other or No DElivery care
Zorgstandaard	Integral Birth Care Standard

List of publications:

This thesis:

1) Women refusing standard obstetric care: maternal fetal conflict or doctor-patient conflict?
Hollander MH, van Dillen J, Lagro-Janssen T, van Leeuwen E, Duijst W, Vandenbussche F.
J Preg Child Health 2016, 3:2. http://dx.doi.org/10.4172/2376-127X.1000251

2) Women's motivations for choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis.
Hollander MH, de Miranda E, van Dillen J, De Graaf I, Vanderbussche F, Holten L.
BMC Pregnancy Childbirth. 2017 Dec 16;17(1):423. doi: 10.1186/s12884-017-1621-0.

3) Fulfilling a need. Holistic midwifery in the Netherlands: a qualitative analysis.
Hollander MH, de Miranda E, Vandenbussche F, van Dillen J, Holten L.
Submitted

4) 'She convinced me'- Partner involvement in choosing a high risk birth setting against medical advice in the Netherlands: a qualitative analysis.
Hollander MH, de Miranda E, Smit AM, de Graaf I, Vandenbussche F, van Dillen J, Holten L.
Submitted

5) Less or more? Maternal requests that go against medical advice.
Hollander MH, Holten L, Leusink A, van Dillen J, de Miranda E.
Women Birth. 2018 Feb 10. pii: S1871-5192(17)30703-5. doi: 10.1016/j.wombi.2018.01.010.

6) When the hospital is no longer an option: A multiple case study of defining moments for women choosing home birth in high-risk pregnancies in the Netherlands.
Holten L, **Hollander M**, de Miranda E.
Qual Health Res. 2018 Aug 12:1049732318791535. doi: 10.1177/1049732318791535.

7) Preventing traumatic childbirth experiences: 2192 women's perceptions and views.
Hollander M, van Hastenberg E, van Dillen J, van Pampus M, de Miranda E, Stramrood CAI.
Arch Womens Ment Health. 2017 Aug;20(4):515-523. doi: 10.1007/s00737-017-0729-6.

8) Psychosocial predictors of postpartum posttraumatic stress disorder in women with a traumatic childbirth experience.
van Heumen M, **Hollander MH**, van Pampus M, van Dillen J, Stramrood CAI
Front Psychiatry. 2018 Jul 31;9:348. doi: 10.3389/fpsyt.2018.00348.

9) Women desiring less care than recommended during childbirth: three years dedicated clinic.
v/d Garde M, **Hollander MH**, Olthuis G, Vandenbussche F, van Dillen J.
Accepted, Birth

Other publications:

1) Verloskundige zorg buiten richtlijnen; enthousiast aan de slag.
M. Hollander, R. Visser, M. Boddé and G. Kleiverda.
TVV 03/2018

2) Zorg op maat in de verloskunde, verklaard vanuit de geschiedenis?
M.H. Hollander, J. van Dillen.
NTOG Vol. 130 oktober 2017

3) Bevalt het in bad?
K. de Jonge, S. Lammerink, M. Putman en **M.H. Hollander**.
NTOG vol. 130, september 2017.

4) Afwijzen verloskundige zorg: moeder-kindconflict of arts-patiëntconflict?
M.H. Hollander, J. van Dillen, A.L.M. Lagro-Janssen, E. van Leeuwen, W.L.J.M. Duijst and F.P.H.A. Vandenbussche.
NTOG Vol. 130 maart 2017

5) Dupliek: Interveniëren mag niet en is niet wenselijk .
M.H. Hollander, mr. dr. W.L.J.M. Duijst.
NTOG Vol. 130 maart 2017.

6) Ouderparticipatie in de perinatale audit: een pilot.
M.H. Hollander, H. Munten, O.W.H. van der Heijden, R. Matthijsse, E. Hink, L. Driessen, M. Janssen and J. van Dillen.
NTOG Vol. 129 Sept. 2016

7) **M. Hollander**, H. Munten, O. van der Heijden, R. Matthijsse, E. Hink, L. Driessen, M. Jansen and J. van Dillen.
Ouders betrekken bij perinatale audit?
TVV 06/2016.

8) Reactie: Actio caesarea- Een gevaarlijke oplossing voor een niet-bestaand probleem.
W. Duijst, I. de Graaf, E. Kingma, **M. Hollander**, J. van Dillen, L. Holten and E. de Miranda.
NJB 40 (2015)

9) Een zwangere die haar hondje uitlaat. Over stomp buiktrauma bij zwangeren.
M. Kenkhuis, **M. Hollander**, P. de Graaff and E. van Westreenen.
NTOG feb. 2014.

10) A case of a four-vessel umbilical cord: don't stop counting at three!
Genevieve Donata Koolhaas, **Martine Helene Hollander** and Harry Molendijk.
Case Rep. Perinat. Med. 2012; 1(1-2): 87–90.

11) Anterior and Posterior Repair with Polypropylene Mesh (Prolift®) for Pelvic Organ Prolapse: Retrospective Review of the First 323 Patients.
Martine H. Hollander, Eduard M.A.M. Pauwels, Guy. M.J.L. Buytaert, and Kristof R.A.A. Kinget.
Journal of Gynecologic Surgery. March 2010, 26(1): 1-5. doi:10.1089/gyn.2009.0032.

12) Medical mystery.
Michiel Eyselbergs, **Martine Hollander**, Patricia Cryns.
Gunaikeia. April 2009, Vol 14 nr 3:90.

13) Prolonged use of atosiban and grade IV intraventricular haemorrhage in an infant born at 29 weeks and 4 days.
Hollander M, Jacquemyn Y.
BMJ Case Rep. 2009;2009. doi:pii: bcr09.2008.0870. 10.1136/bcr.09.2008.0870. Epub 2009 Mar 17.

14) Unilateral renal agenesis and associated Müllerian anomalies: a case report and recommendations for pre-adolescent screening.
Hollander MH, Verdonk PV, Trap K.
J Pediatr Adolesc Gynecol. 2008 Jun;21(3):151-3. doi: 10.1016/j.jpag.2007.05.005.

15) Gestational diabetes: a review of the current literature and guidelines.
Hollander MH, Paarlberg KM, Huisjes AJ.
Obstet Gynecol Surv. 2007 Feb;62(2):125-36.

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Table 1 of 4

Year	INTENDED Courses, workshops, study group & journal clubs (include html link)	Dates (from/to)*	Duration (days, hours)	Self study / preparation time	EC Points
Year 1	• Introduction day Radboudumc (link)	01-08-2014	1 day	-	0.5
Year 2	• Scientific Integrity course (all PhD's, link)	23-09-2016 / 30-09-2016	2 days	-	1.0
Year 3	• BROK course (for PhD candidates who perform research involving human subjects and/or patients, link) # • Journal Club	September 2017 All year	2 days 2 hours monthly	4 days 2 hours	1.5 -
Year 4	• Journal Club	All year	2 hours monthly	2 hours	-

Table 2 of 4

Year	INTENDED Seminars & lectures (include html link) (international talks and posters)	Dates (from/to)*	Duration (days, hours)	Self study / preparation time	EC Points
Year 1	-				
Year 2	Why woman want Other or No DElivery caRe, oral presentation ECPM conference Maastricht (presentation 152) https://www.eiseverywhere.com/ehome/144836/oral Poster Traumatic Experiences Associated with Childbirth: the TEACH study (poster 154) and poster Obstetrical Care Provider's Attitude to Patients who Disagree with Medical Advice (poster 153) https://www.eiseverywhere.com/ehome/144836/POSTER	17-06-2016 17-06-2016/18-06-2016	11 minutes	8 hours	?
Year 3	Why women want Other or No DElivery care, poster presentation ECIC Stockholm Poster Traumatic Experiences Associated with Childbirth: the TEACH study, ECIC Stockholm Why women want Other or No DElivery caRe, oral presentation ICM conference in Toronto (http://www.midwives2017.org/cfm/index.cfm?It=914&Id=1&Se=2&Lo=2&Sv=&Rn=1&AF=202&AA=Download&AD=2128,734)	2505-2017/27-05-2017 19-6-2017	N/A 30 minutes	1 hour 4 hours	 6
Year 4	-	-	-	-	-

Table 3 of 4

Year	INTENDED (Inter)national symposia & congresses (include html link)	Dates (from/to)*	Duration (days, hours)	Self study / preparation time	EC Points
Year 1	Cardiology and pregnancy	22-01-2015	1 day	-	5
	Perinatal audit Nijmegen	27-01-2015	3 hours	-	2
	Society for Maternal Fetal Medicine San Diego USA	02-02-2015/07-02-2015	1 week	-	22
	Regional evening Arnhem	03-03-2015	3 hours	-	2
	Perinatal audit Nijmegen	19-03-2015	3 hours	-	2
	IGO conference Rotterdam	22-03-2015/24-03-2015	3 days	-	18
	Perinatal audit Nijmegen	27-05-2015	3 hours	-	2
	FMF conference Crete Greece	21-06-2015/25-06-2015	1 week	-	30
	Pediatrics seminar	02-07-2015	1 hour	-	1
	NVOG evening	30-09-2015	3 hours	-	2
	WPOG conference	15-10-2015	3 hours	-	2
Year 2	NVOG committee foetal ultrasound	21-01-2016	1 day	-	6
	Symposium court-ordered caesarean Rotterdam	28-01-2016	4 hours	-	?
	SCEM obstetric medicine Ede	17-03-2016	1 day	-	6
	Implementation project NVOG/KNOV guideline	18-03-2016	1 day	-	?
	NVOG gynaecongres	19-05-2016/20-05-2016	2 days	-	12
	European conference of perinatal medicine Maastricht	15-06-2016/17-06-2016	3 days	-	24
	Teach the breech conference Amsterdam	30-06-2016/01-07-2016	2 days	-	12
	NVOG gynaecongres	18-11-2016	1 day	-	6
	Symposium intra-uterine growth restriction Utrecht	24-11-2016	1 day	-	6
Year 3	Symposium vulnerable pregnancies	13-02-2017	4 hours	-	3
	Farewell symposium Hans Beekhuis	19-5-2017	4 hours	-	3
	ECIC Stockholm	25-05-2017/26-05-2017	3 days	-	18
	ICM Toronto	18-06-2017/22-06-2017	5 days	-	30
	SCEM symposium beweging in geboortezorg	12-10-2017	1 day	-	6
	Symposium een autonome geboorte	11-11-2017	1 day	-	6
Year 4	Society for Maternal Fetal Medicine Dallas USA	31-1-2018/3-2-2018	4 days	-	24
	Fetal Medicine Foundation	24-06-2018/28-06-2018	5 days	-	30

Table 4 of 4

Year	INTENDED Teaching (e.g. supervision students, lectures; include html link) (national/regional/local talks and posters)	Dates (from/to)*	Duration (days, hours)	Self study / preparation time	EC Points
Year 1	Response classes for medical students	Different dates	1 hour	-	-
	Class for intensive care nurses	November 2015	1 hour	1 hour	-
	Course for midwives/GP's	October 8th 2015	1 day	1 day	-
Year 2	Supervision Master student paper on Chapter 5	December 2015-February 2016	3 months	40 hours	-
	Supervision Master student on Chapter 6	February 2016-April 2016	3 months	40 hours	-
	Response classes for medical students	Different dates	1 hour	-	-
	Supervision 2 nursing student's paper	September 2016-January 2017	4 months	40 hours	-
	Presentation on what if doctor and patient disagree, WPOG seminar	10-03-2016	2 days	4 hours	12
	Residents' teaching on my project	4-11-2016	2 hours	4 hours	-
	VSV teamtraining course (tutor)	6 different dates	4 hours	2 hours	-
	SAVE'r course Medsim Eindhoven	5 different dates	1 day/time	1 hour/time	-
Year 3	Response classes for medical students	Different dates	1 hour	-	-
	Presentation at symposium "pregnant women and baby's", Nijmegen	24-2-2017	4 hours	2 hours	6
	Presentation at VSV Arnhem	9-3-2017	1 hour	2 hours	-
	Presentation at local midwives meeting	15-3-2017	1 hour	2 hours	-
	Presentation on what if doctor and patient disagree, WPOG seminar	16-3-2017/17-3-2018	2 days	4 hours	12
	Presentation at SCEM symposium pregnancy and mental health	23-3-2017	1 hour	2 hours	6
	Presentation (session) at KNOV study day (clinical midwives, nationwide)	24-3-2017	2 hours	1 hour	6
	Presentation at regional meeting acute primary care	17-5-2017	1 hour	2 hours	-

	SAVE'r course Medsim Eindhoven	3 different dates	1 day/time	1 hour/time	-
	Placenta practicum	5 different dates	2 hours	1 hour	-
	Presentation at regional meeting on WONDER study, Doetinchem	29-08-2017	3 hours	1 hour	2
	Student meets patient	Approx. 5 times	1 hour	-	-
	Ethics class for interns	10 times	2 hours	2 hours	-
	Teaching midwifery master students in Rotterdam	10-10-2017	4 hours	1 hour	-
	Presenting at the POP symposium	10-10-2017	1 hour	1 hour	-
	Presentatie Vereniging voor Obstetrie verpleegkundigen Nijkerk	2-11-2017	1 hour	1 hour	-
	Presentatie op CPZ jaarcongres	10-11-2017	1 hour	1 hour	-
Year 4	Supervision Masterstudent on Chapter 8	November 2017-February 2018	3 months	40 hours	-
	Response classes for medical students				
	SAVE'r course Medsim Eindhoven	Different dates	1 hour	-	-
	Student meets patient	Approx. 5 times	1 day/time	-	-
	Placenta practicum	Different dates	1 hour	-	-
	Ethics class for interns	Different dates	2 hours	-	-
	Kennisnet symposium	19-01-2018	1 day	4 hours	6
	SCEM congres Zorg rond de pasgeborene	29-1-2018	1 day	1 hour	6
	Openingssymposium digipoli Heerenveen	16-2-2018	½ day	1 hour	3
	Presentation on what if doctor and patient disagree, WPOG seminar	7-3-2018/8-3-2018	2days	1 hour	12
	VOG symposium	01-11-2018	1 day	4 hours	6
	KNOV annual symposium	20-11-2018	1 day	1 hour	6
	PAOG nascholingsdag verloskundigen	29-11-2018	1 day	2 hours	6
	Symposium clinical midwives	30-11-2018	½ day	2 hours	6

Dankwoord

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Dear Frank. We met at a time in my life when I was going through something you might call an early midlife crisis. I can't imagine what you must have thought of me, but you loved me anyway. I don't always feel like I deserve your

unwavering support and unquestioning love, but I do know we are going to grow old together.

Lieve Morgan en Julian. Het klinkt als een cliché, want dit lees je vaak in dankwoorden van proefschriften, maar het boekje is eindelijk af. En mama zal niet meer op zondag achter de computer gaan. Dat beloof ik. Wat ben ik trots op jullie, mijn lieve schatten!

Curriculum Vitae

Martine Helene Hollander was born in Leiderdorp on January 11th 1975 as the eldest of two daughters. After graduating from the Stedelijk Gymnasium in Leiden in 1993, she was fortunate enough to be able to start medical school the same year, at the Vrije Universiteit in Amsterdam.

She graduated in 1999, and became ANIOS (resident not in training) obstetrics and gynecology at the Kennemer Gasthuis ('de Deo') in Haarlem. While there, she discovered that getting a training post would be a long road, and would most likely involve a PhD, which *she really didn't want to do*. A local community midwife recommended that she went back to school to retrain as a midwife. After a telephone call to the local midwifery academy, it was negotiated this would only take one year. A year at the Kweekschool voor Vroedvrouwen (KVV) in Amsterdam saw her graduating with the rest of her class and becoming partner in community midwifery practice "Doevendans" in Apeldoorn.

After three years and many home births, blood turned out to be thicker than water, and she went back to the hospital to seek out a training post. After several years in both Apeldoorn and Tilburg, she was accepted for residency at the Vrije Universiteit in Antwerp, Belgium (professor Yves Jacquemyn) in 2006.

She graduated as an obstetrician-gynecologist in September 2011, and back in the Netherlands, she continued with a fellowship in perinatal medicine in Zwolle (Dr. Jim van Eyck). After completing this fellowship in 2014, she worked for 6 months as chef-de-clinique at the Canisius Wilhelmina Hospital in Nijmegen, after which she was offered a staff position at the Radboud University Medical Center in Nijmegen, where she works to this day.

Almost immediately after starting her current post, in September of 2014, she commenced work on a research project, that has culminated in this thesis.

Martine is married to Frank. They have two children: Morgan (2011) and Julian (2012).